

ERADICATION OF LEPROSY THROUGH



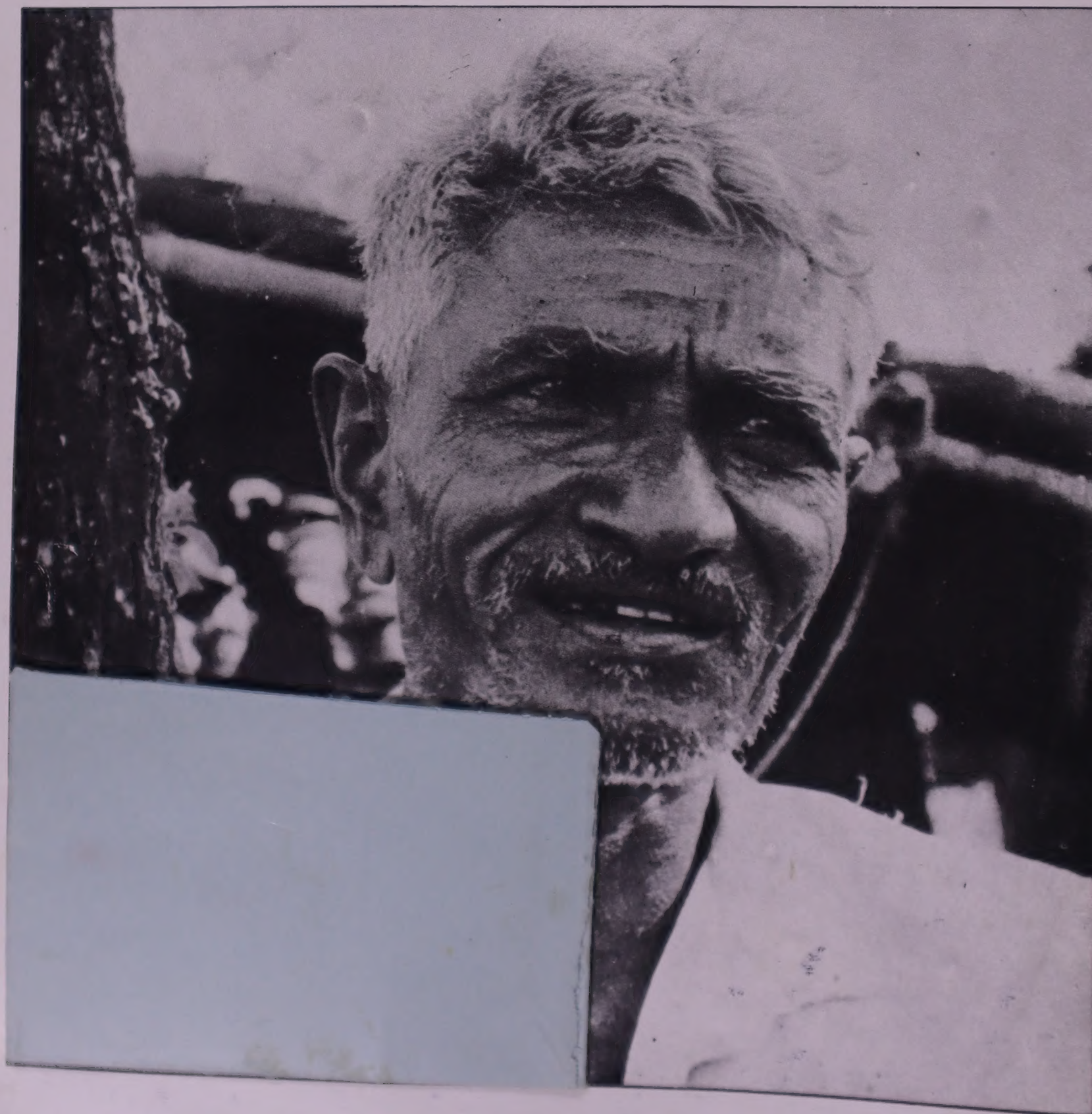
- MASS AWARENESS
- HEALTH EDUCATION
- COMMUNITY PARTICIPATION

A MASTER PLAN

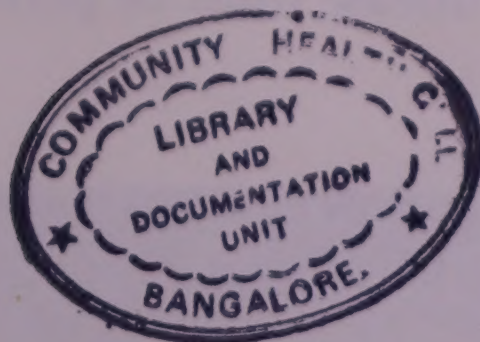
GANDHI MEMORIAL
LEPROSY FOUNDATION

HINDI NAGAR, WARDHA-442103
MAHARASHTRA

“When I look back, I realise, it was so silly of me to have been so disappointed and given up hope. I almost believed that my body, my youth, my life...everything would move into slow, decaying death. And, I would be an outcast...”



COMMUNITY HEALTH CELL



This is Gulab Shankar Bavane, a 57-year old blacksmith from Barbadi village, near Wardha in Maharashtra.

Years back, when he was 23, strange things started happening on his body. Smooth, silky patches appeared on the skin, discolouring it at some places. Painless and non-itchy, they stealthily developed, inviting no attention from an unsuspecting and ignorant Bavane.

Eventually, to his shock and dismay, Bavane learnt that the patches on his skin were the signs of a disease, known to be the 'much-feared kusht-rog'!

Young, able, and energetic Gulab Shankar was heart-broken. What would happen to him now? Where would he go? How would he live? Several questions welled up within him, desperately seeking the right answers and help.

At Barbadi, his disturbing questions were not to go unanswered.

For, nearby was Sewagram, with its reassuring Gandhian solace and treatment for leprosy afflicted persons. And, further down, was another seat of learning in medical science and help for leprosy cure. By the time Bavane's disease had come to light, several social workers

and medical personnel had already fanned out to villages like Barbadi, to survey, detect and treat the cases of leprosy, and to motivate the people to take a rational view of the disease and seek scientific advice.

The result was that, within days of Bavane's detection, anti-leprosy drugs started working within him—commencing the arrest of the devouring bacilli and resisting its further scourge.

Scientific medicine, a rational awareness and health education brought back Gulab Shankar's confidence. And, like hundreds of his fellow-men in the village, he too stayed with his family, worked from dawn to dusk, married, and adjusted into the mainstream of life—away from social ostracisation and despair.

For Gulab Shankar Bavane, the times had been fortunate.

But for the millions and millions of others with their ignorance, religious chastisements, superstitions and social stigma, does leprosy cure stand a chance like this?

For them, will there be an awakening? If so, when?

“In India, we’ve undertaken a national campaign against leprosy...but fear and social prejudice still conspire to prevent large numbers from seeking treatment. In this, the time factor is all important. The disease must be permanently consigned to the limbo of history”.

Indira Gandhi



May 1981. New Delhi.

In her address to the World Health Assembly, the late Prime Minister of India, Smt. Indira Gandhi called upon the developed nations to help the developing world in the task of eradication of leprosy.

At the meeting, she reiterated:

“In India, we’ve undertaken a national campaign against leprosy...but fear and social prejudice still conspire to prevent large numbers from seeking treatment. In this, the time factor is all important. The disease must be permanently consigned to the limbo of history”

The words had been spoken. The challenge had to be met.

Yet, the task is far from easy.

Realising the stupendous nature of the problem, the Ministry of Health and Family Welfare constituted a working group of scientists and social work experts in leprosy, under the Chairmanship of Dr. M.S. Swaminathan, to devise a plan of action.

And, in February 1982, the Group suggested a three phased strategy: Mass Awareness and Participation Phase from 1982-85; Attack Phase from 1985-90; and Consolidation Phase from 1990-2000.

The following objectives were outlined for the First Phase.

- Create an awareness and interest among the people.

- Develop positive attitudes and practices towards effective action to control and prevent leprosy with available resources and technology.
- Enlist participation of all sections of the population.
- Develop and initiate local voluntary organisations to sustain and promote NLEP.

The Working Group observed that a massive swing has to be generated conducive to people's participation. The communication strategy must be so conceived as to enliven the people's enthusiasm and sustain the swing over a long period.

A Difficult Task Indeed

Although necessary steps to implement the recommendations of the Working Group were taken, significant achievements or spectacular results in motivating the agencies aimed at, remained a difficult goal to be reached.

The realities of the problem and several other constraints on the methodology made the task stay beyond the grasp of commendable results.

The conclusion is that, conventional approaches and the techniques of yesterday are just not sufficient to achieve the targets—within the given time frame.

The Time Has Come For A More Dynamic Approach

With the objectives of the NLEP clearly defined on one side, and the achievements in the Programme

measured on the other, it is easily appreciable that the time has come now to take off from a more dynamic springboard of action.

Because, the disease in all its ugly ramifications continues to haunt our society, even today.

Yes. The time has come to accelerate the fight. The time is now.

An Initiative By GMLF

Against this background, the Gandhi Memorial Leprosy Foundation, volunteered to draw up a Master Plan for the resurgent action. The idea was to bring together many more agencies and resources under one

comprehensive umbrella, than hitherto achieved.

It was envisaged that such an exercise would offer a wide variety of useful suggestions and ideas from groups, individuals and organisations who were involved in leprosy control and similar mass scale operations.

This Master Plan is the crystalisation of such an amalgamation of views, suggestions, opinions, case studies, facts, figures and conclusions.

It is submitted with the objective of giving a new thrust to the National Leprosy Eradication Programme, in the years to come.

PREFACE

In the overall programme of leprosy eradication, medication and corrective surgery are only a part of the total solution. What is equally important is to transform ingrained attitudes—of individuals as well as that of the community at large.

Not many people are aware of the fact that the fruits of modern research have already begun to benefit millions of patients. That today, more than ever before, a good prognosis is possible; that not only can a leprosy patient be saved from social sequestration, but those already sequestered can be restored to their families and original environment and integrated once again into the mainstream of life. The fight against leprosy thus acquires a more intensive and intricate dimension. Centuries of folklore, superstitions and prejudices, dogmas and stigma associated with the disease need to be replaced with a positive, enlightened view and by civilised social behaviour.

It is to such an awakening of the minds of the society besides the creation of etiological solutions to the problem of leprosy that a large number of individuals and institutions have dedicated their services since the past many decades. While it is an appreciable fact that the entire network of activists committed to this national cause has covered extensive ground in their respective fields of operations, the realities of the leprosy problem today are far from creating a feeling of reassurance or satisfaction about its immediate control and eradication.

Many of the goals that were outlined many years ago, still evades achievements of consequence.

In this context of persisting inadequacies and shortcomings of many an activity in the present NLEP implementation, the need for a more resurgent result-orientation becomes more than evident. Realising the value of such an orientation, the Gandhi Memorial Leprosy Foundation, in its true spirit of dedication to the cause of leprosy control in India, mooted the idea of bringing together a wider range of resources, talent and know-how under one roof and crystalising this Master Plan, as an enhancement to the activities and attention-areas outlined by the Dr. Swaminathan Committee.

While the drawing up this Master Plan was envisaged to be widely-encompassing in scope, for the improvement of the NLEP, the mobilisation of efforts behind such an exercise was also viewed to be no less a gigantic task with involvement from a number of sectors. In order to systematically organise the inputs of this Master Plan, a series of special Task Force Meetings were called upon—involving a host of individuals from fields as diverse as medical services, sociology, mass communications/management science, voluntary health and social welfare organisations, Government Departments and Institutions, advertising agencies, health education units, international foundations, charitable organisations, universities and educational institutions...among a number of others

related to leprosy control work and similar social cause activities.

The outcome of these discussions, meetings, exchange of notes, suggestions and views indeed resulted in the creation of an immensely fruitful base to formulate this Master Plan document.

It has been very encouraging to witness the response that GMLF, as the initiators of this exercise, received from all quarters, throughout the authoring of this Plan—be it in the structuring of the substance or the formatting of its presentation.

The Master Plan has been presented in two parts, the first part being a Summary and the second, the actual Plan along with the Appendices.

My sincere feelings of gratitude and appreciation reach out to every member who participated in the Task Force

as also to the large number of committed individuals from all sectors who dedicated their valuable time and energy to help formulate this Master Plan. It has also been an inspiring experience to observe the enthusiasm of the members of the Gandhi Memorial Leprosy Foundation, and their efforts in the preparation and production of this document. I am particularly indebted to Dr. S.D. Gokhale, our Chairman, for the wholehearted support he offered to this project; for his valuable participation in the meetings of the Task Force; and for the numerous improvements suggested to make this Report cohesive and instructive.

S.P. Tare
Director

CONTENTS

• SUMMARY	8
What is this Master Plan all about?	
How does it contribute to the NLEP?	
• Health Education so far. Has it really risen upto the goals?	9
• The shortcomings in Health Education. What exactly are they?	10
• Rectifying the shortcomings.	11
• Budget Proposal	16
• Recommendations of this Master Plan—An Overview	17
• Consultant Members of the Task Force	20
• THE MASTER PLAN	21
• MASS AWARENESS	23
What is Mass Awareness? What is its purpose?	
How will it serve Leprosy Eradication?	
• How Mass Awareness of NLEP can be improved?	25
Case for a Consortium of Advertising Agencies—Communication Workshops	
• Mass Media Potential—An Overview	27
• HEALTH EDUCATION	31
What is Health Education? How should Health Education be conducted in the NLEP?	
• Why is Health Education important?	34
• What are the shortcomings that Health Education faces today?	37
How can they be solved for better Leprosy Eradication?	
• How to make the implementation of Health Education more effective?	45
Job Chart for Leprosy Workers—Production of Health Education materials—A Primary Health Care model...	
• COMMUNITY PARTICIPATION	51
What does Community Participation mean?	
How can it be made more effective?	
• SCREENING, RESEARCH, COORDINATION AND EVALUATION INFRASTRUCTURE	54
Screening Committee—Social Science Infrastructure—Coordinating Agency—Evaluation—Documentation	
• ROLE OF VOLUNTARY AGENCIES NETWORK	60
• PRE-BUDGETARY IMPLICATIONS	64
• Appendices	65

SUMMARY

What is this Master Plan all about ? How does it contribute to the NLEP ?

The problem of leprosy is a very complex one and has several socio-medical overtones.

Although medical science has made breakthroughs in leprosy cure with drugs such as D.D.S., Rifampicin, Clofazamine for a combination of therapies, it is an axiomatic truth that the technological advances are far ahead of our social psychology or the mass capacity to accept revolutionary ideas.

Perhaps that is why, there is a contradiction between our acceptance of leprosy cure through medical science and our social attitude to the disease, existing even today.

Hence, any attempt to solve the problem of leprosy has not only to tackle it on the scientific and rational planes, but also on the emotional and psychological ones.

The disease has still not achieved the importance of being regarded as a national health problem. Nor has its eradication efforts galvanised the people

to get involved in it, as a national 'movement'.

In a nutshell, this Master Plan identifies these problematic areas, analyses the short-comings in the present system, and suggests a more dynamic and result-oriented action plan.

While the Plan recognises the importance of all the other components in the NLEP, it gives one primary subject a greater emphasis throughout.

The subject of Health Education.

That's because, the concept of Health Education is so all-embracing that it brings in its wake, a variety of other influencing factors that strike at the root of the leprosy scourge.

The Plan is also based on the premise that a systematic and scientific health education process will integrate all the other activities in favour of the 'massive swing' expected amidst the people—thus consolidating the efforts of the National Leprosy Eradication Programme.

Health Education so far. Has it really risen upto the goals?

Right from the inception of the NNLCP (later expanded in scope as the NLEP), the role of Health Education was given significant importance.

It was attributed with as much emphasis as Case Detection and Treatment.

The activity, hence, was dove-tailed into the medical pattern of leprosy control called S.E.T. (Survey, Education and Treatment).

However, when it came to the actual implementation, the Education component of this device was decided to be conducted as a separate activity since it called for an entirely different infrastructure aimed at the masses. The 'E' in S.E.T. thus, more or less meant the education of the patients or the suspected cases.

The 'E' in S.E.T. A Little Success... A Great Deal More To Be Done

A review of the Health Education activities done so far in India reveals the following picture:

- The population understands that leprosy manifests as pale patches on the skin.
- A good proportion of new cases voluntarily approach medical examination, every year.
- There is general decline in the severity of the social stigma and around 85% of

the cases continue to stay within their family units.

- Dehabilitation of leprosy patients from jobs, family and social set-ups shows a downward trend.

(It is necessary to note here, that the above conclusions were drawn from the experiences in the field work done and from reports of a number of leprosy centres/units. It is not the inference from any specific study conducted country-wide.

Then again, these observations were from centres and areas where the NLEP implementation has been comparatively satisfactory. There are many areas in the country where the Programme has not yet been implemented in significant measures, which can make vast differences to the noticeable gains above, when projected on a national scale.)

In Health Education, there seems to be much more that can be done in India.

And, a long way to go.

The shortcomings in Health Education. What exactly are they?

An evaluation of the Health Education work done so far reveals the following areas where results are not satisfactory;

1. In the curriculum for different training courses in health education, the weightage given to the subject of leprosy control was inadequate.
2. Among the teaching staff in majority of training centres, the number of those who have had exposure to health education was poor. This has resulted in the subject either not being taught or being superficially dealt with so far.
3. Health Education has been grossly neglected in the training of Medical Officers. They, thus have not appreciated its importance and hence have not emphasised it in the implementation of the Programme.
4. In the training of Non-Medical Supervisors also, the subject was not given sufficient stress. Hence they were unable to guide the field workers in the activities concerning health education.
5. The monitoring procedures for Health Education activities were almost nil, in the early stages of the Programme and whatever was done later has not been effective in getting a comprehensive or scientific data—qualitatively and quantitatively.
6. There is a huge shortage of good Health Education aids, for use during training and for field work. The absence can be noticed not only in the hardware but also in the correct software.
7. Awareness of the subject of Health Education among general medical practitioners and Health Services was low. Hence, the activity has taken a back-seat in their day-to-day work.
8. A considerable insufficiency in good social science research data was noticeable in areas like the stigma problems, attitude of the people to the disease, acceptability/non-acceptability of the diseased, the common curability concept, the econometric factors, and the impact of Health Education and communication among the people. This lack of information and its management, has in turn, been a handicap to the effective implementation of the Programme.

The question now is, 'How do we remove these flaws' to put Health Education in the right focus?



Rectifying the shortcomings

Step 1: Get A Fundamental Grasp Of The Subject Of Health Education.

Health Education has been defined in many ways by many experts.

The sum and substance of these varied opinions is, perhaps, best expressed in a WHO Technical Report, "Health Education, like general education is concerned with changes in knowledge, feelings and behaviour of people. In its most usual form it concentrates on developing such health practices as are believed to bring about the best possible state of well-being."

It is the on-going and universal process of involving the people to learn about health and the warding off of diseases. It is also the imbibing of reassurance and a positive outlook, so that a resort to corrective measure is taken rationally, should diseases and illness occur.

Salient features of Health Education:

- Health Education can be organised as a self-learning process.
- Health Education can be a process of learning from others.

- Health Education consists of proper communication of ideas.
- Health Education entails the correct knowledge of health and diseases for proper building-up of attitudes and behaviour.
- Health Education also envisages the acquiring and developing of skills for the health educator so as to educate, communicate and motivate the receiver of the message.
- Health Education is not necessarily the teaching of medical and health subjects to undergraduates. People in all walks of life need to be educated frequently on health practices and related behaviour as a continuous process and in totality.
- Health Education must take full cognisance of all the influencing factors in any situation, to motivate human behaviour.

From the above, it is clear that by Health Education, what one has to achieve is not the learning of a few 'do's and don'ts' about health and prevention of diseases, but a totally positive outlook to initiate the desired behaviour in the society for the maintenance of general health.

Overall Health Education vis-a-vis Leprosy Control

Health Education in the context of leprosy eradication must, therefore, take this overall concept into view and not rigidly restrict it to only preventing the particular disease.

Because, in improving individual and community hygiene and health consciousness lies the foundation of a healthy society free from diseases or resilient to such attacks.

Only when the building up of this basic health base occurs, can one aspire for the achievement of the 'Health for All by 2000 AD' objective in general, and the total eradication of leprosy in particular.

Step 2: Identify The Factors That Will Rectify The Shortcomings

After understanding the basics of Health Education, and the importance for its re-vitalisation in the NLEP, what is now necessary is to point out the precise factors that will bring about the desired change:

These include the following:

- Strengthen the health education component in the S.E.T. system.
- Improve the Methods of result-orientation,, especially in the area of shortcomings
- Accelerate the co-ordination between the medical field and health education, information and broadcasting and other sectors.

- * Outline the priorities and activities for the social groups which contribute to health education work.
- * Devise a fail-safe mechanism for mass media utilisation on more scientific ways to invoke people's participation.
- * Define the areas to be delegated to voluntary organisations in the field and also outline the fields from where financial and other aids (Govt./Others) will accrue.
- * Point out the aspects where effective social research studies ought to be done, and help create the infrastructure for such practices.
- * Improve the quality of the delivery of the Programme, measure its impact on the masses and develop methods to sustain the "swing"

Step 3: Apply The Mass Awareness Health Education, Community Participation Formula

Against the factors thus outlined, and the imminent need to refurbish the activities to achieve the target of total eradication of leprosy by 2000AD which is about 180 months away, this Master Plan brings forth a 3-pronged formula for action: Mass Awareness; Health Education and Community Participation.

The three components of this formula

for action are discussed comprehensively in this Master Plan under different chapters. They are also described briefly, on the following pages.

Mass Awareness: The 'Selling' of Leprosy Eradication

The first and foremost factor that would ensure the success of any mass movement, is the shaping of the minds of the prospective audience to receive the messages conducive to the movement.

In the action plan suggested, the Mass Awareness strategy does that.

(While this strategy was emphasised in the report of Dr. Swaminathan Group the approaches suggested here are submitted as boosters to the Committee's plans. In fact, the Mass Awareness strategy as discussed in this Master Plan, can be considered as an operations plan of the Group's views).

The approach to mass awareness as suggested in this plan primarily brings out two significant conclusions:

- (a) Make mass awareness attempts more professional, accountable, involve more scientific tools, techniques and talents.
- (b) Make mass awareness activities more comprehensive.

It is with these objectives that the Master Plan propounds the application of the marketing management concepts, setting up of screening committee, coordination of agencies, and training of communication

personnel in health education and leprosy eradication subjects.

Health Education: Stress On The Training Of The Trainer And Streamlining Of Activities

The action plan suggested for Health Education in this Master Plan brings in its wake, the entire gamut of activities necessary on the subject, in a more dynamic and streamlined fashion.

The chapter on health education highlights the need for strengthening the health education base in the programme, setting up of standards and know-how update, education of the end-users and motivation of the influencing agencies. This is intended to be achieved through several new means and methods aimed at the respective audiences.

Techniques like social science research, evaluation and project monitoring, training of the trainers, medical science methodology, etc. have all been discussed in the chapter.

Since the subject, as mentioned earlier, is the cardinal area of attention for this Master Plan, considerable indepth studies and suggestions have been made both in the hardware and software necessary for creating the required impact.

Community Participation The Impetus For People's Involvement

The ways and means of promulgating the movement through village leaders, NSS volunteers, NCC cadets, Bharat Scouts and Guides, welfare clubs, social service workers, anganwadi workers, philanthropists, Government educational institutions, teachers, parents, doctors, family members and other individuals are discussed in the chapter.

Also included in the chapter is a unique experiment in Community Participation methodology, which has been tried in a specific area with remarkable success in the Programme. It has been suggested for a national-scale adoption at the grass root level.

Step 4: Set up Screening, Research, Coordination and Evaluation Infrastructure

(a) SCREENING AND QUALITY CONTROL CELL

Due to the present state of affairs of an influx of health education and mass awareness inputs which either do not portray the efforts of the Programme in the best perspective or the aspects of the disease in angles which are more favourable to its eradication, the Master Plan also suggests the setting up of a Screening and Quality Control Cell for the conduct of the NLEP.

- * Study, plan and set down the precise guidelines for the content and kind

of health education materials.

- * Screen, approve and finalise the content and type of the materials in accordance with the guidelines.
- * Co-ordinate the activities of its subsidiaries to promote uniformity of message and materials for effective impact and feed-back.
- * Approve, finalise and administer the utilisation of mass media inputs and check the effectiveness of the actions and inputs.
- * Comprise a compact structure for its functioning with representatives from all sectors like Government, CHEB, WHO, GMLF, NLO, DAVP, AIR, Mass Communication Agencies, Film Industry, etc.

In the setting up of the Screening Committee, it must be noted that the persons selected would be limited in number and relatively more available for frequent meetings and discussions on its activities.

To have a better streamlined operation, the Cell would suitably be de-centralised at State and Regional levels. This is important since the communications materials must be made to suit the local dialects and culture, which is best understood and carried out by local agencies than at the Central level.

(b) SOCIAL SCIENCE RESEARCH CENTRES.

The present status of Health Education must be radically improved with sufficient back-up of research resources.

The quality of delivery of the Programme, along with the attainment of success can all be made more effective only with a scientific and systematic social science research base.

For this, the need for research centres set up by the voluntary agencies involved in leprosy and other health education work in the country is imperative. The research centre would aim to offer a comprehensive wealth of information and facilities for research studies in the following areas:

- *Operational Research
- *Basic Research
- *Communication Research

An elaboration of these objectives and the areas of activities are discussed in the Chapter on the subject.

The encouragement of such social science research facilities on a national scale must be given adequate priority since it is only through a mass build up of factual data base that the leprosy problem can be eradicated medically and socially.

Coordination of Voluntary Agencies

Today there is a strong voluntary sector involved in leprosy control work.

Although Health Education in leprosy, being a part of the National Leprosy Eradication Programme of the Government of India is a responsibility of the Government primarily, a strong network of voluntary organisations is supporting and collaborating with it, in the NLEP.

This Master Plan makes various recommendations and suggestions which are applicable to both the Government sector as well as the voluntary agencies involved in the Programme. These are being suggested with the basic objective of channelising their activities into four basic areas for an impetus to the NLEP. They are:

1. Extending their services either in the area immediately surrounding those covered by governmental centres or at State level to help governmental work in health education. The agencies can also take up independent programmes in health education.
2. Mobilising the participation of influential groups in the society like social welfare clubs, societies, educational institutions, NSS, NCC, Bharat Scouts and Guides, Armed Forces, industries, large religious groups, etc.
3. Producing health education materials and aids suitable to the regional and local conditions and making them available to the Government for use in their centres.
4. Feeding the mass media with news, features, programmes, and other publicity inputs on leprosy eradication.

But then, every voluntary institution may not be able to undertake all these activities either due to shortage of resources or lack of expertise. Hence, the ideal operating system would be that, one voluntary agency take up only one activity in their area and/or surrounding areas while another may take up one or

more programmes, in their immediate vicinity.

In specific terms, the services of the voluntary agencies may be brought under four main action paths, for better dynamism, integration and acceleration of the NLEP:

- Identification of suitable voluntary institutions with expertise and resources for participation at 1) Local level 2) State level 3) Regional level. This identification may be carried out with the help of GMLF, TLM, and NLO.,
- Allocation of the areas in which each of these institutions can participate.
- Identification of the manner, area or programme in which each of these institutions can participate.
- **Liaising** with respective State Governments to promote and offer **patronage** to these institutions.
- **Extension of financial support to, and/or encouraging such support to Voluntary Institutions to work outside their own spheres.**
- Start a dialogue with all the voluntary agencies to find out the exact potential and scope of work and the willingness to participate in the NLEP and point out such areas of participation.
- The Master Plan also gives an exhaustive description of the above area identifications, in the chapter.

Evaluation And Documentation

The present mechanism for evaluation of health education is in the form of evaluation

teams at State level. Some States have already appointed these teams and are on this job.

It is advised that, the teams may be asked to consult experts with social science background or in health education, while carrying out these evaluation and thus improve the quality of findings through scientific, social, science research methodology interview, case studies etc.

All the efforts to the scientific orientation of the programme can lead to little result unless documentation also follows through in its true spirit and practice.

At a glance, one can realise that at present the record pertaining to health education is maintained in different styles by different agencies or not maintained at all. This discrepancy needs to be rectified.

The Budget Proposal

To implement the recommendations of the Master Plan, it would require a considerable amount of financial outlay.

A chapter has been segmented in this Master Plan which puts forward a plan of action for raising such funds or for making the programme pay by itself, in several areas.

However, while working on a model budget, the guidelines of the Swaminathan Committee will prove useful as is discussed in this Chapter.

The Recommendations of this Master Plan

An Overview

Subject	Recommendations	Agency Involved
• MASS AWARENESS	<ul style="list-style-type: none"> • Introduce scientific mass communication tools and techniques, for the development of the Mass Awareness strategy. e.g.: Market Research, Media Research, Copy/Visual Recall Pre-Tests, Test Marketing, Depth Interviews, Positioning Tests, Readership/Viewership Studies, OTS/OTH etc. • Set up a Consortium of Advertising Agencies, with regional representation. De-centralise the activities of the Consortium with overall monitoring. • Provide autonomous status, responsibilities and power to the Consortium, under a Screening Committee. • Issue directives to Films Divn., AIR/Doordarshan, DAVP, Govt. Publications Depts., PR Agencies, Press etc., to provide sufficient exposure to NLEP campaign. Provide financial incentives and other concessions for these agencies to develop proper mass communications software. 	Information & Broadcasting Ministry/ Advertising Agencies D.A.V.P. Social Science Research Centre
	<ul style="list-style-type: none"> • Issue directives to Posts & Telegraphs, Indian Railways, State Transport Depts., Petroleum Corporations, Public Sector Undertakings etc to sponsor advertising space/materials/activities for the NLEP campaigns. 	Communications Ministry, Railway Board, State Govt, Petroleum Ministry, Transport Ministry, Ministry of Commerce.
	<ul style="list-style-type: none"> • Set up a Screening Committee for the laying down of guidelines, testing and evaluation of Mass Awareness and Health Education materials and implementation. Screening Committee to have autonomous status, responsibilities and powers with regional representation—State/Regional level sub-committees. Screening Committee to monitor the entire activities and materials in the Leprosy Control Programme, which are aimed at Mass Awareness and Health Education. 	Ministry of Health and Family Welfare/DGHS (Lep.)
• HEALTH EDUCATION	<ul style="list-style-type: none"> • Provide sufficient emphasis on health education in the NLEP activities and make available the necessary funds. 	DGHS (Lep.)

Subject	Recommendations	Agency Involved
	<ul style="list-style-type: none"> • Provide training facilities in health education, by starting more training centres for the trainers. Emphasis to be made on leprosy control training. 	DHS (State-level) State Leprosy Officers GMLF
	<ul style="list-style-type: none"> • Provide in-service training for leprosy workers in health education. 	State Leprosy Officers
	<ul style="list-style-type: none"> • Involve other health workers and orient them towards leprosy eradication work. e.g.: General Medical Practitioners, Para Medical Staff, Health Services Personnel etc. • Appoint/Utilise Screening Committee's infrastructure, for identifying the correct and uniform Health Education materials. • Identify voluntary agencies or commercial sectors for the production of standardised health education materials, in line with Screening Committee's guidelines. 	Directorate of Health Services (States)
	<ul style="list-style-type: none"> • Create an effective machinery for distribution of the materials to the grass root levels, to standardise procurement and distribution. 	DGHS (Lep) GMLF
<ul style="list-style-type: none"> • SOCIAL SCIENCE RESEARCH 	<ul style="list-style-type: none"> • Establish leprosy research as a priority area and provide financial incentives, other benefits, to agencies such as ICSSR, ICMR, UGC, IIMC etc, for leprosy research. • Encourage research facilities in medical and social science fields and provide adequate financial support/grants/scholarships etc for leprosy research. • Motivate voluntary agencies to either set up social science research resources or utilise existing facilities in the field for leprosy research. 	Ministry of Health & Family Welfare, Ministry of Education Ministry of Social Welfare ICMR, ICSSR Ministry of Health & Family Welfare Ministry of Education Voluntary Organisations
<ul style="list-style-type: none"> • EVALUATION 	<ul style="list-style-type: none"> • Make evaluation systems more scientific employing modern research analysis techniques, more result-oriented methods, etc. • Issue directives to present evaluation teams at State level, to incorporate health education evaluation methods. 	DGHS (Lep.)

Subject	Recommendations	Agency Involved
	<ul style="list-style-type: none"> • Seek help of professional data processing/ evaluation agencies for evaluation of health education component in the leprosy control work. • Incorporate a feed-back mechanism in the present system of data collection to get a more comprehensive picture of the health education work done by the leprosy workers. 	
•INFRASTRUCTURE	<ul style="list-style-type: none"> • Create a district level post of health education officer for more energisation of this activity. The post may be titled 'District Health Education Officer'. 	DGHS (Lep.)
•COMMUNITY PARTICIPATION	<ul style="list-style-type: none"> • For mobilising support of NCC Cadets, NSS Groups, Bharat Scouts & Guides, Youth Organisations, YMCA/YWCA etc. Issue directives 	Ministry of Defence/ Ministry of Education/Ministry of Sports & Youth Affairs/Ministry of Social Welfare GMLF
	<ul style="list-style-type: none"> • Orient community leaders, opinion makers, senior citizens at district, taluk and block levels for mobilising support to leprosy control activities 	Ministry of Social Welfare/State Rural Development Boards
	<ul style="list-style-type: none"> • Issue directives and/or motivate general medical practitioners, practitioners of traditional medicine, teachers, housewives, police personnel, social workers and other state-level operators. 	GMLF Voluntary, leprosy agencies State Govt Depts/Boards/Agencies.
•CO-ORDINATING AGENCY	<ul style="list-style-type: none"> • Set up a Co-ordinating Agency for implementation and monitoring of the NLEP activities in a more result-oriented fashion. • Involve active participation of voluntary agencies in the Coordination Agency operations. • Ensure regional representation in the Coordination Agency, and also compactness of structure for thorough operations 	Ministry of Health & Family Welfare/DGHS (Lep.)/GMLF
	<ul style="list-style-type: none"> • Ensure direct responsibility of Coordinating Agency for the functioning of the Screening Committee. The Coordinating Agency may be made responsible for the setting up of the Screening Committee. 	GMLF DGHS (Lep.)
	<ul style="list-style-type: none"> • Ensure direct responsibility of Coordinating Agency for planning, executing, supervising and evaluating the activities under all heads of the NLEP Master Plan. 	

THE CONSULTANT MEMBERS OF THE TASK FORCE, FOR THE PREPARATION OF THIS MASTER PLAN

- Abhyankar, Shri P.D.
Communications & Graphic
Art Consultant, New Delhi,
- Ajith Kumar, Shri R.
Advertising & Editorial
Consultant, New Delhi
- Annamma Joseph Smt.
Programme Officer
UNICEF, New Delhi
- Bhakta, Shri Dahyabhai
Film Director
Bombay
- Chettan, Shri B.S.
German Leprosy
Relief Association
Madras
- Chiplunkar, Shri N. R.
Chief Executive
Spectrum Communications
New Delhi
- Choubey, Dr. N. P.
Sr. Research Officer
Indian Institute of
Mass Communications
New Delhi
- Devendra Kumar, Shri
Director
Centre of Science for
Villages, Wardha
- Diwakar, Shri R.R.
Member, GMLF
Bangalore
- Giri, Shri S.R.
Health Education Officer, GMLF
Midnapore, W. Bengal
- Gokhale, Dr. S.D.
Chairman, GMLF
Bombay
- Kanwaljit Singh, Smt.
Mg. Director
React Advertising Pvt, Ltd
New Delhi
- Khanna Rajani, Smt.
Nutrition Specialist
NIPCCD
New Delhi
- Mehendale, Shri M.S.
Pune
- Mehra, Shri Sudhir
Management Consultant
New Delhi
- Muthu Koya, Shri.
Chief of Exhibition
DAVP, New Delhi
- Mutatkar, Prof. R.K.
Research Advisor
Centre for Social Science
Research, GMLF, Wardha
- Nilankanta Rao, Dr. M.S.
WHO Consultant
Bangalore
- Ohri Punam, Smt.
Research Assistant
NIPCCD,
New Delhi.
- Pifaratna Dr. C.
Health Education Officer
WHO Regional Office
New Delhi
- Prabhakar Rao, Shri V.
Health Education Officer
GMLF
Chilakalapalli
Andhra Pradesh
- Prasher Amita, Smt.
Films Consultant
New Delhi
- Rao, Dr. C.K.
Dy. Director-General
Health Services (Leprosy)
Govt. of India,
New Delhi
- Sharma, Dr. R.S.
Member, GMLF
Wardha
- Shiv Kumar, Shri
Research & Referene Division
Ministry of Information &
Broadcasting, New Delhi
- Subbanna, Shri S.
Jt. Director
Directorate of Field Publicity
New Delhi
- Tare, Shri S.P.
Director, GMLF
Wardha
- Tuli Shri. J.
Information Officer
WHO Regional Office
New Delhi
- Wele, Shri D.S.
Asst. Director
GMLF
Wardha
- Yellapurkar, Dr. M.V.
Jt. Director Health Services
Govt. of Maharashtra
New Delhi

THE MASTER PLAN

Leprosy has been identified as a disease by health scientists and workers of modern science. They identify all the stages of the disease, understand its etiology and profess total cure.

However, the majority of the people, even today look at leprosy not merely as a disease but also as a curse or a manifestation of the wrath of God. They are ignorant about the causative factors and harbour suspicions to the claims of curability professed by medical and health practitioners.

The gap between 'what the disease is' and 'what people believe it to be', creates problems—hampering the efforts to control the disease and bring about its ultimate eradication. To fight the disease called leprosy, it is thus also necessary to fight this mental block among the mass population and make a significant breakthrough.

Such a viewpoint is seen to have been stressed by almost every scientific group involved in the field of leprosy eradication, wherever in the world. To cite a very recent confluence of this thought, is to review the words of His Holiness John Paul II at the meeting of a Working Group of 14 scientists at the Pontifical Academy of Sciences, Vatican, between May 28-June 1, 1984. The Pope observed, "for the sake of those people (leprosy afflicted), efforts must be increased everywhere to ensure that those who are still condemned to a sort of civil-death can re-discover life, improve its quality and find in society a place corresponding to their human dignity, for like all other people, they are made in the image and likeness of God".

Later, stressing the importance of Education, the Working Group reported: "Education has a vital role to play in more effectively dealing

with leprosy. More useful training about leprosy for medical and post-graduate students or health workers in leprosy endemic countries is required. New social science research approaches provide insight into how best to involve people and to enable them to realize (a) that leprosy is an infectious disease, not a moral or religious chastisement, (b) that it can be prevented or cured without the development of deformity (c) and that patients with this, like other infectious diseases when appropriately treated can be productive members of their community."

It is an axiomatic truth that no disease can be controlled by the administration of drugs alone, if it is of the proportion that leprosy is, today. Without the right cooperation and the correct willingness and participation from the people themselves, eradication is not possible. What is required is an intensive educational approach to change the attitudes which are negative, into responses and participation that are totally positive and encouraging.

After exhaustive studies and analyses in these lines, social science experts and behavioural pattern observers have come to the conclusion, that such massive change of attitude can be brought about only through a systematic and strategic application of a series of promotional stimuli. Forming the crux of this Master Plan recommendations, these application stages have been classified under three heads:

- *Mass Awareness
- *Health Education
- *Community Participation

The following pages of this Report illustrate these three factors and also elaborate on the related activities that would make these the successful springboards to achieving greater results for the NLEP.

MASS AWARENESS



What is Mass Awareness? What is its Purpose? How will it serve Leprosy Eradication?

Essentially, mass awareness refers to that state of mind wherein the recipient quality of any communication evokes a mental response in a pattern, attributed to that sponsored stimuli.

Mass awareness also means the creation of such desired response en-masse.

The purpose of mass awareness, thus, is to bring about a mental experience or the preparedness for the experience, among the masses, through the transmission of information or ideas and the sharing or exchanging of information or ideas. It is carried out with the objective of changing attitudes among the masses and conditioning their behaviour.

As far as the problem of leprosy eradication is concerned, mass awareness shall mean the creation of a positive awakening in the minds of the people—about the disease, its ramifications, characteristics and scientific solutions for its cure and eradication. This implies the use of correct methods of communication, right message content and proper evaluation of the application.

What is the present picture of mass awareness?

The existing mass awareness level about leprosy is, as has been noted, grossly dismal. The compounded effect of superstitions and stigmatised conditioning has obliterated the realities about the disease from the people's minds.

To cut this massive barrier, handed down through the generations, and within the time limits before us, calls for bold, dynamic and scientific communications onslaughts.

This means, the application of modern mass communication models and motivational techniques.

How Can Mass Awareness Of NLEP Be Improved?

The best results in Mass Awareness for leprosy control and health education can be achieved, if the activities are re-cast in more scientific and dynamic approach moulds.

It is in this context that the planners of this Master Plan see the need for infusing new communications—blood into the Programme. After a series of reviews and analyses of the shortcomings in health education delivery and overall mass awareness procedures in the present approach, it was concluded that the business of creating Mass Awareness be left to the modern, professional practitioners in persuasion and communications technology.

A significant step in this direction would be to entrust the Mass Awareness part of the Programme to the professional advertising agencies who have at their command, a much larger exposure to the scientific tools and techniques of marketing and advertising.

Since decades, these agencies have been solely engaged in the business of offering professional talent and skills to thousands of sponsors of products, services and facilities to help them persuade the masses in buying or enjoying these products and services. Over the years, advertising know-how in the country has been exposed to several new theories (and models in research) methods and evaluation. With this knowhow, advertising practice has gained considerable professionalism and scientific outlook.

Almost every major advertising campaign that hits the country's population carries the imprint of excellent research studies and test

methodologies for achieving maximum recall and impact.

Concepts like Depth Interviews, Random Surveys, Group Discussions and other techniques in Market Research, to get down to the fine points of psychographic profiles of the target audience are done prior to campaign development.

Even after the creation or during it, research methods like copy research, media effectiveness studies, OTS/OTH Studies, Readership and Viewership Profile studies, Couponing and Director Response Research, Positioning and Repositioning, Pre-Tests and Post-Tests etc. are carried out by these agencies before embarking on a national-scale launch.

All this, to ensure that every rupee or every moment spent on Mass Awareness or Advertising fetches the right value in the actual field operation to improve the quality of delivery of the Programme.

Advertising Expertise For NLEP

In the case of the NLEP, where creating sufficient Mass Awareness and impact on the people's minds have largely eluded the efforts, a dynamism in application of modern communication technology is called for.

More so, in this case, we are not fighting a medical problem alone but attempting to also break through a massive block of deep-rooted social prejudices, attitudes and misunderstandings, which have sedimented coral-like, over the generations, on the very psyche of the nation.

To break this mental block, the unleashing of any less effort just wouldn't do.

Mass Communications—The Case For A Consortium of Advertising Agencies

For the actual creation and production of mass awareness software, the concept of using a Consortium of Advertising Agencies is mooted for implementation. The consortium will work within a sub-committee format, directly under the aegis of the Screening Committee in matters relating to Advertising.

This concept gains support due to the fact that while no single agency can handle the actual coordination and implementation of the Awareness programme within the limited time periods or constraints, leaving it to all voluntary organisations to operate would only bring the problem to square one.

The consortium approach would also result in collective thinking and problem solving in the field, which is vital, considering the multifarious socio-medical manifestations of the disease among the people.

However, while the consortium would be a come-together of communication talents, care is to be taken not to create a hotch-potch of the communication itself with too many suggestions staking claim or getting accepted. The modus operandi would be while only four agencies at the most would create the actual software, the directions, propositions, and strategies would be discussed by all and given a consensus. In carrying out the operations each agency in the group with its regional representation would be able to achieve results more effectively.

Monitoring of activities would be done by the agency concerned in its specially allocated area, and reports of feedback, evaluation studies etc. would be obtained from all the regions by the coordinating/screening committee in a systematic format. The final report, which would be a periodic collection of this data, would be created by the Screening Committee and submitted to the coordination Agency for its review.

Improving the Quality of Communications: Communications Workshops

While it would be the aim of the Screening Committee to ensure a cohesive, integrated and correct communication quality, in order to make these gains, it would be necessary to orient the practitioners in the subject as mentioned earlier.

To carry out this, a series of workshops would be conducted by the Committee on various aspects of the leprosy problem and its communication. The workshops would be attended by all voluntary agencies, mass media, advertising practitioners, graphic artists, film directors and similar mass media representatives.

Besides the conventional media workshops, conventions and seminars to organise non-conventional media operators would also be considered by the Committee.

These workshops, Seminars and Conferences will inculcate a discipline to the programme on the following lines:

- a) Guidelines for communications in leprosy control
- b) Activities and programmes possible in the field.
- c) Specific communications project identification for voluntary agencies.
- d) The techniques of professionalism and scientific message creation.
- e) The result oriented and research based implementation techniques
- f) The basic know how in health education subjects.
- g) Message screening feed back evaluation guidelines, support and aid.
- i) Central Governmental/State Government/Department roles in the activities.
- j) Case studies and reviews of public service communications.

- k) Incentives and concessions available in supporting the activities etc.

The Mass Media Potential— An Overview

The coverage for NLEP's Mass Awareness is to be accelerated through the entire gamut of mass media vehicles available in the country. Apart from conventional media, an extensive network of non-conventional media ought to be tapped.

Fortunately, the media scene in the country is gaining unprecedented growth. With the advent of the electronics media and the improvement of the quality of publishing, making in-roads into far flung regions is ever easier today than in the earlier stages of the Programme.

A checklist of media vehicles is noted below for understanding at a glance the potential for coverage of the Programme.

1 Documentary Films

Documentaries on leprosy control work, Socio-medical aspects, voluntary agencies.

2. T.V.

Talks on leprosy control, group discussion, play, live coverage of control work, case studies, rehabilitation, medical facilities and achievements, film & reviews and screening, cultural events coverage involving leprosy patients, joint sponsored activities with voluntary organisations.

3. Video

In-film advertisement on leprosy Control Health Education etc to be done on commercial Video Cassettes.

4. Press

News coverage on leprosy centres, articles and features on voluntary agencies, Interviews with social workers/leprosy rehabilitation centres, case studies of leprosy patients, free slogans on leprosy eradication, concessions and discounts on leprosy advertisements, awards for articles and features on leprosy.

5. Cinema

Concessional tariff for advertisement films on leprosy

Concessional tariff for cinema slides on leprosy.

Free advertisement space for leprosy slogans and cinema posters, cinema hoarding, cinema tickets.

Positive portrayal of leprosy and its control work in Commercial Films.

Production of films portraying leprosy eradication, rehabilitation.

Encouraging and promoting mini-festivals of Award Winning films for leprosy collection drives.

6. Radio

Talks on leprosy for special groups of villagers, women, social workers, medical professionals, NCC, NSS, Scout & Guides, Students etc.

Radio seminars/group discussions on leprosy with experts.

Special radio programmes on Gandhi Jayanti Day, Leprosy Week etc.

Radio plays based on leprosy.

Short, small skits, or programmes during intervals between main programmes.

Concessions on advertisements tariff for leprosy advertisements.

Free broadcast of leprosy slogans once daily

Interviews of leprosy workers, voluntary organisations, events and rehabilitation case studies of leprosy patients.

7. Railways

Prominent coverage of leprosy in railway time tables.

Concessions to leprosy patients made more prominent, and attracting attention of all people.

Concessional advertisement space for leprosy ads in time tables.

Posters on leprosy eradication, rehabilitation, community participation, health education etc. to be displayed on railway compartments.

Posters in waiting rooms, billboards and hoardings on platforma, walkways, parking lots etc.

Leprosy slogans on railway platform

Leprosy slogans on railway platform tickets, travel warrants, concessional group tickets, ticket booking forms, arrival/departure time-table boards. etc.

Orientation to all railway doctors, assistance staff, railway workers, colony members on leprosy eradication, detection, treatment and social awareness.

Organisation of leprosy detection camps, cultural programmes, essay competitions seminars and similar activities among railway colonies/staff.

8. State Transport

Posters, billboards at the bus stations, buses, bus stands, bus tickets.

Advertisements in bus time tables, concessional ticket cards, arrival/departure boards, platform gangways, bus panels (inside and outside) stickers, luggage carriers, etc.,

Orientation on leprosy detection, treatment, cure and social awareness to transport workers, families.

Distribution of leaflets, pamphlets to transport staff/families/passengers.

Joint promotional programmes with voluntary agencies.

Free slogans over public announcement systems/closed circuit TVs.

Free leprosy advice/information at information counters.

Concessional tariff for advertisement space.

Slogans on leprosy in state transport advertisements/announcements.

9. Indian Airlines

Donation slogans for leprosy on airline tickets, boarding cards, baggage tickets.

Concessional tariff for leprosy ads on airport lounges, gangway display signs closed circuit TV systems.

Free slogans/concessional advertisement tariff on airline time-tables, in-flight magazines, airlines news letters, for funds-contributions.

Free information/advice on leprosy, distribution of social awareness and health education materials at information counters.

Orientation for airline medical staff on leprosy, seminars/joint programmes for social awareness among airline staff, families workers.

10. Post & Telegraphs

Free slogans on postal articles like inland letters, postcards, envelopes, aerogrammes etc.

Special First Day Cover and Stamp Cancellation on leprosy.

Posters at post office counters.

Free slogans on telegraph forms on leprosy, health education, social awareness.

Concessional tariff for advertisements on leprosy in postal dept. publications.

11. Outdoor

Concessional tariff for hoarding rentals painting etc. for leprosy advertising.

Special rebates for leprosy message on commercial hoarding displays, wall paintings for advertisers.

Sponsoring incentives to petrol station bill boards, window displays on leprosy eradication, health education and social awareness messages.

12. Petrol Station

Sponsoring incentives to petrol stations for distribution of health education materials, leprosy eradication literature, leprosy seals/stickers and for offering bill-board space window displays

Special incentives for the above outlets for printing leprosy messages in cash memos.

13. Matchbox Media

Rebates on printing costs of match boxes with leprosy messages.

Posters in match factories, sales depots on leprosy awareness, health education.

Publicity promotional schemes on matchbox labels with leprosy messages.

14. Folk Arts

Themes on leprosy eradication, social awareness, health education.

Skits, stage crafts on leprosy eradication messages.

Dialogues/Acts on the above.

Messages on tickets

Slogans on publicity materials.

Special charity show incentives like entertainment tax deduction on shows with leprosy themes.

Awards/Incentives for best performances for leprosy causes.

15. Song and Drama

Themes on leprosy eradication, health education, social awareness.

Special incentives/awards/recognitions for artists, composers and producers in the unit for projecting leprosy eradication themes

16. Field Publicity

Special incentives for projecting themes on leprosy eradication, health education, social

awareness, among field publicity unit artists.

Inclusion of leprosy slogans/messages in publicity materials, exhibition panels, publications for mass distribution.

17. Mobile Publicity Units

Special incentives/project aids for promoting leprosy eradication

Concessional financial aids/arrangements for operations of NLEP.

Survey/Detection and feed-back incentives during promotions.

Tax concessions, entertainment, tax deduction, licence/motor vehicles tax concessions, during leprosy control work.

18. Rural Cooperatives

Posters on leprosy at retail outlets

Messages/slogans on ration cards, ration card forms.

Slogans/messages on cash memos.

Tinplates/display boards at sales counters and retail outlets of Agricultural Co-operatives dealing in Fertilizers, seeds etc.

19. Hospitals/Dispensaries/Primary Health Centres/Clinics

Posters, tinplates, leaflets at counters, waiting rooms, wards/corridors.

Direct mail shots to doctors, general medical practitioners, health service personnel.

Advertisements in medical journals newsletters, pharmaceutical Co. etc.

Since almost all of the above media mix comes under the purview of the Ministry of Information and Broadcasting, implementation and active participation of the media in the Programme shall not pose much of a hurdle.

With the Screening Committee's streamlined output on the one side and the Centre and State level joint participation and promotion, on the other the involvement of the media in promoting the NLEP shall go a long way.

Special incentives for media patronage is also suggested in this Master Plan, to motivate them into wholehearted participation. It is inevitable that any national movement of this nature would fall flat, unless a commendable support from the media is sought for its promotion.

Then again, there is the question of costs. Since leprosy is a public health problem and of a much greater sociological complexity than many other problems, mass awareness and health education exposures in the media shall be best served if the activities organised without depending entirely on the national budget or the budget envisaged in this Master Plan.

Good media exposure costs require

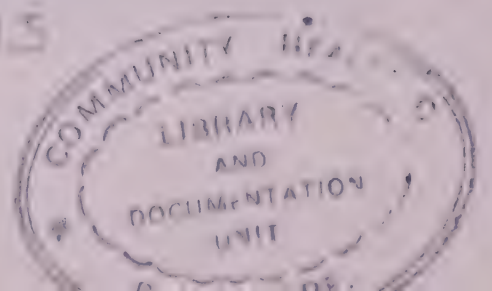
tremendous amount of budget outlays. To avoid such a huge drain in the programme budget, the Chapter also discusses the potential of tapping the private industrialists and voluntary agency sectors, for sponsorship of the media exposure in a manner calculated to be mutually beneficial.

Professional mass communication agencies like advertising agencies, market research agencies, media concessionaires etc. need to be called in, for such a vast-scale media operation. The cost efficiency of obtaining such professional advices is emphasised since these agencies are more competent in terms of resources, data base, experience and capabilities of utilising the media to ensure the best value for money.

HEALTH EDUCATION



DIS 315
31 3044



What is Health Education? How should Health Education be conducted in the NLEP?

The Policy statement of Post-Congress Workshop on health education, held in February 1984 at Wardha, states, "Health education refers to the process of assimilation of scientific health knowledge, attitudes and behaviour in the health culture of the people. Health education in leprosy aims at ensuring community participation in leprosy control programmes. Health Education, therefore, addresses itself to the patients, their families, to the community and all components of health services."

The basic principle of health education is the belief that every individual, group and community can be educated, if they are provided with learning and the abilities for assessing the problems, in planning remedies and in providing facilities to implement these remedial measures, against health hazards.

A sound health education programme, hence, brings under its scope all individuals, groups, institutions and organisations in all situations and sections of the population where teaching and learning activities could take place, between them.

In the context of leprosy eradication, the Congress identified and agreed that the following factors were the relevant issues in health education for the NLEP, and that they hold the key-answers to a better result-orientation.:

AT THE PATIENT LEVEL

- Health education is a part of patient care and is aimed at preventing deformities, improving foot-care, etc.
- Health education delivery should be properly recorded and maintained with the patient-charts.
- Health education should involve a 2-way communication process—the doctor recognising the therapeutic value of

listening to the patient, and assessing the feed-back.

- Health education training courses and refresher seminars need to be offered to all workers, in addition to the existing diploma/certificate courses.

AT THE METHODOLOGY LEVEL

- Health education through mass media exposures should be recognised for creating general awareness.
- Health education media must be supplemented with modern, wide-spreading networks like: video communications, TV sponsored programmes, radio sponsored programmes, etc. The use of video communications is also stressed for training of the trainers.
- Health education attempts should also be channelised through the traditional media like puppet shows, folk-lore, street-plays, circus, etc.
- Health education messages need to be thoroughly screened to avoid fear and stigma creating appeals, before releasing to the mass audience.
- Health education activities ought to be based on scientific approaches, and research-based conclusions—achieved through a strong data base involving micro computerisation, wherever necessary.

AT THE TRAINING LEVEL

- Health education must be inculcated with special stress in the training of supervisory staff so that they keep up the spirit and substance in motivating the field staff.
- Health education of the patients and the community must be so formulated so as to ensure patient care and community participation in the subject.

AT THE COMMUNITY LEVEL

- Health education should aim to develop among people, significant attitude and behaviour to achieve better health on their own. Or, seek professional help, if and when needed.
- Health education must be directed to solve problems of public facilities, family dis-organisations, land grabbing, de-habilitation, etc.
- Health education should enlighten the people to offer facilities for conducting leprosy control programmes; at individual and group level; help in locating socially acceptable areas for leprosy clinics; co-operate with the health agencies in case detection and holding.
- Health Education should focus on participation of special groups such as: NSS, NCC, Bharat Scouts & Guides, National Youth Services besides adult groups like teachers, nurses, journalists, lawyers, legislators among others.
- Health education should also aim at preventing derogatory references to leprosy in commercial and other media. It must educate the mass media to portray the positive side of the disease, and not the repugnant side. The prevalence of interpretation of the disease, like references such as, "alcoholics should not be treated like lepers" etc., ought to be changed.
- Health education must be inherent in fund-raising programmes—achieved by portraying the positive appeals of cure and rehabilitation, rather than negative, emotional appeals through disfigurement portrayals etc.

AT HEALTH CARE LEVEL

- Health education objectives, tools, methods and references must be made familiar to all health services personnel at all levels—including medical and para-medical.
- Health education must be so identified to suit concepts that are universally applicable as well as regionally meaningful.

- Health education should be transmitted using messages which are easily assimilated within the applied culture system.
- Health education must be carried out with expert advices and contributions from communication and education professionals.
- Health education personnel should be trained and exposed to social science methodologies/workshops—practised by national and international agencies in the field.

AT THE RESEARCH LEVEL

Research Objectives: To improve health education methods and content so that people accept the basic essentials of leprosy control programme and participate in it.

Topics of Research: In addition to the areas identified at the pre-Congress Workshop, the following topics were also identified.:

- Evaluation of health education tools and methods in terms of (a) leprosy control (b) community participation.
- Messages absorbed by the people and their duration
- Effectiveness of communication processes in various cultures due to variation in (a) literacy levels (b) prevalence and (c) deformity rates.
- Viability of health education methods to suit new treatments regimens such as MDT.
- Impact of school surveys on community.
- Relative effectiveness of using various social groups for creating awareness in the community.
- Motivation and perception of leprosy workers, towards the disease, its impact on the effectiveness of health education.

The Congress also agreed that these newly identified social science research studies would require active involvement of larger and more modern research inputs.

Why is Health Education Important?

The problem of leprosy eradication is a very complex one and the disease carries serious social overtones. More than what it is medically, it is what people think about it and how they look down upon it that has added to the complexity of fighting this scourge.

As already stated the gap between 'what the disease is' and what people believe it to be creates problems—hampering the efforts to control or eradicate the disease.

Hence, any solution towards this task has not only to offer epidemiological and therapeutical methods, but also a whole range of activities that bring knowledge and awareness among the people to erase their existing images of the disease and elicit positive participation in its eradication.

Health education is one such subject that offers the leprosy eradication practitioners, this potential. The viewpoint is seen to have been stressed by almost every scientific group involved in the subject, all over the world.

The humanitarian aspect of the Leprosy Eradication Programme has been a matter of deep concern for social worker and missionaries. It is significant that His Holiness the Pope John Paul II felt it necessary to call upon the scientists to make efforts to save the leprosy patients from civil-death and restore to them their human dignity.

Nearer home, the importance of health education in leprosy control was stressed right from the inception of the National Leprosy Control Programme, and was included as a vital aspect of the pattern—Survey, Education and Treatment (S.E.T.), promulgated for adoption by Dr. Swaminathan Committee.

While the strategy of Survey and Treatment took off with giant strides, being largely a direct medical and health services programme, the education component somehow got conducted, or even relegated, as a separate activity with relatively limited achievements.

The reasons, perhaps, can be easily assessed. For one thing, an activity such as health education is far more wider in its sweep and carries in its wake an entire educational process of scientific health knowledge, changing of attitudes and behaviour in the health culture of the people—a task that calls for much more concentrated efforts and training, which fall beyond the purviews of the routine health services set up.

Secondly, while detection and treatment of leprosy patients offer direct and tangible results not to mention the emotional satisfaction of seeing visible proof of cure concept of health education is more an intangible and academic proposition, which only reflects in an overall perspective without specifics or concrete evidences. This, in a system fraught with quantitative accountability and materialistic reckoning, finds difficulties for implementation.

Understandably so, as far as the medical pattern of leprosy control is concerned the SET methodology has rendered Health Education, a pace of progress that is comparatively slow.

Yet, this does not mean that the picture is all that totally bleak, if one were to study the results of health education activities in some parts of the country.

Before one arrives at any hasty conclusions, it is pertinent to also understand that the above readings were drawn from the experiences in the field-work done by voluntary agencies and from reports of health education activities

available. The conclusions are not based on any systematic scientific studies conducted country wide.

Moreover, such results were noticed in areas where the implementation of the Programme was commendably high. There are still a large number of areas where the effect of the programme has not given significant results. On a national-scale projection, such pace of progress would make vast differences to the picture of health education.

A Great Deal More To Be Done

From the assessment of the Health Education programme carried out so far, it is evident that it has been able to succeed to a limited extent—in as much as the statistical returns available do not represent the national profile.

Much remains to be done in spreading the message of Health Education and one way to achieve any significant success would appear to be to project the whole programme as health-oriented without undue emphasis on fear of leprosy:



What Are The Shortcomings The Health Education Faces Today? How Can They Be Solved For Faster Leprosy Eradication?

In the level of achievement in health education, in the past two decades, the analyses of many a scientific and realistic review done prior to the framing of the Master Plan identified the following major areas of shortcomings. The committees and workshops also suggested the solutions to the problems.

In Medical & Health Services:

The Shortcomings:

The health and medical personnel, are today apathetic towards leprosy-- largely due to the lack of sufficient exposure to the subject-- and they share the same fear and misconceptions as the general population. They need to be oriented towards a scientific and rational attitude to the disease.

Action Suggested:

For this, it is imperative that all Government and other health/medical personnel be periodically involved in activities supporting the leprosy eradication programmes.

Directives ought to be so formulated as to make State Government responsible to ensure (a) the teaching of leprosy in all public health/medical training centres, (b) the offering of health education guidance by all medical and health personnel to patients of leprosy and the community in a defined structure, is similar to family planning models, (c) the treatment of leprosy patients and diagnosis, in every hospital/dispensary and clinic (d) the staff under medical/health depts. of all categories are assigned constructive programmes during leprosy week, every year.

In Training of Medical Cadre:

The Shortcomings:

The curriculum for teaching of leprosy and its control jointly by the Indian Medical Council and GMLF is not being implemented in all the medical colleges of the country.

Action Suggested:

- * The Government/Indian Medical Council should issue strict directives both for implementation of the syllabii in the institutions and for submitting the feed-back on its practice.
- * All universities must be so directed both by the Government and the Indian Medical Council to include at least one question on leprosy, in the final MBBS examination.
- * State Governments should insist that the medical colleges hold a one-day seminar/symposium on the subject, involving their teachers, from four to five disciplines/departments.
- * There should be a full day seminar/symposium in medical colleges every year, for the final year students, highlighting leprosy eradication.
- * Seminars should also be organised by the State Governments, for doctors in Government service and public health departments at different places in a year, so that in two or three years, every doctor in such services would have been exposed to the problem of leprosy at least once.
- * Refresher courses on leprosy control must be organised in every state, through the

branches of the IMA, for covering the general medical practitioners (Private practitioners). GMLF has undertaken such orientation courses for the past ten years. Other major voluntary institutions can also take up this activity in their adjacent areas or in their States. The Government of India must devise a suitable financial grant scheme to meet the expenditure of these competent voluntary agencies for this activity.

- In the training of leprosy worker, more numbers of lecturers on health education is a vital necessity for all categories of trainees. A sample curriculum and number of lectures is given in Appendix (2).
- For training in-service para-medical workers, the duration of the training should be made not less than 2 months.

Ten to twelve senior non-medical supervisors may be selected to do the training at State level. Wherever qualified and experienced Health Education Officers, with exposure to leprosy control, are available, they may be selected.

- Leprosy teaching must be effectively introduced in all the training institutes schools for general health staff, including those such as family planning training centres, schools of nursing, etc., (for sample of curriculum see Appendix(3))
- In order ensure that these programmes are result-oriented, a senior staff member of the institute should be trained in leprosy in a recognised training institute.
- Seminars/symposia must be conducted by these institutes also, on the lines suggested for medical colleges.
- Similarly, all these centres should also conduct one day seminars on leprosy for the trainees in every batch.
- In order to orient and motivate all paramedical workers who are in-service under the medical and public health departments, two-day workers who are in-service under the medical and public health departments, two-day workshops must be

conducted at the primary health centre level once a year. With such workshops conducted for at least three years, every such para-medical worker would get an opportunity to attend the training at least once. The travel cost of this training may be met from the budget of the scheme under this they are involved. The expenses for local arrangement, should however be provided from the allocation for leprosy eradication.

In Training The Trainers:

The Shortcomings:

Health education has been grossly neglected in a number of training courses in the country - whether they are for medical officers, non-medical supervisors, para-medical workers, teachers, private practitioners, medical students of workers of voluntary agencies.

In addition, in the original plan of NLCP, it was visualised that every leprosy worker in the field right from medical officer to para Medical Worker will do health education activity. From the fifth plan the Government of India has created a post of Health Educator, at the level of the Leprosy Control Unit.

The results are found as follows

- 1 The Health Educator, often untrained in proper health education techniques, is not equipped to do the job effectively.
2. The area of the control unit is too large for the Health Educator to cover--- particularly since no independent transport is provided.
3. With the arrival of the Health Educators, the field workers have abandoned whatever little health education work, they were previously doing.

Action suggested:

The immediate solution to this shortcoming is to revive the previous policy of every field worker carrying out health education activity. The post of Health Educator at the control unit level may be withdrawn.

It will be desirable to create the post of District Health Education officer (Leprosy),

who will be entrusted with the responsibility of guiding and supervising health education activity. He will be in charge of the Mobile Health Education Unit recommended by the Leprosy Working Group appointed by the Scientific Advisory Committee of the Cabinet. He should preferably be a person with a Diploma in Health Education, with 20 days orientation training (same as given to non-medical supervisors), or one who has an experience of over 10 years in field, and is trained in Health Education (Leprosy) for two months.

In Hardware and Software Aids

The Shortcomings:

As far as the availability of health education materials are concerned, what is primarily lacking is an element of professionalism and scientific approach to the inputs. Health Education, as has been explained, involves considerable communication needs and this calls for extraordinary grasp on the techniques and tools of communication.

The lack of a co-ordinated and holistic approach to the inputs have made considerable communication gaps during the training as well as field operation in health education. Both in software and in hardware.

The absence can be felt in the quantum and quality of lectures in health education, as well as in the number of qualified teaching staff, who have hand exposure to scientific health education disciplines.

Action Suggested

On Hardware:

The following criteria may be applied to each category of health worker for providing hardware.

- a) their academic background
- b) manner in which they will be doing health education
- c) the group which they will handle

- d) type of transport available
- e) Financial involvement

Paramedical Worker:

A paramedical worker as the field worker directly in contact with the public will need the following:

- i) A practical hand-book on how to conduct health education activities.
- ii) Flash cards—to be carried whenever he is on duty.
- iii) Set of banners—to be put in villages where the conduct survey, and also at the time he conducts any health education programme.
- iv) Stencils for writing wall slogans
- v) Pamphlets, leaflets—to be distributors with discretion to those who show interest.
- vi) Booklet for leprosy patients

It is needless to mention that all material should be in local language.

Non-Medical Supervisor:

The non medical supervisor will have twin responsibilities—firstly to guide and supervise the health education work done by the paramedical workers and secondly to cover some special groups themselves. They should be supplied with following material:

- i) A practical handbook on health education this will be a different book than the one suggested in item (i) above.
- ii) Flash cards.
- iii) Slide projector and set of slides
- iv) Matter for posters
- v) Mobile exhibition
- vi) Photo album
- vii) Set of banners
- viii) Stencil for writing wall slogans
- ix) Booklet for leprosy patients

District Health Education Officer

The district health education officer will also have twin functions of planning, guiding and supervising health education activity of leprosy workers in the district as also to do health education of some selected groups. It will also be necessary to consider supply of transport to the D.H.E.O. (leprosy) for his speedy and independent movement in the district with costly and delicate equipment.

The DHEO should be supplied with the following:

- i) A practical hand book on health education
- ii) 16 mm film projector
- iii) Three four good films on leprosy.
- iv) Slide projector with two three sets of slides.
- v) Tape-recorder with cassettes on leprosy
- vi) Flash cards
- vii) Photo album
- viii) Microphone set and accessories
- ix) Mobile exhibitions 2-3 different sets
- x) Equipment for puppet shows
- xi) Stencils for writing wall posters
- xii) Matter for posters, cinema slides
- xiii) Printed pamphlets, leaflets.
- xiv) Booklet for leprosy patients

Medical Officer

The medical officers in leprosy are posted in leprosy control units and they will need material and aids which are available for health education in the whole area. With this purpose in view, they should be supplied with the following.

- i) A practical hand-book on health education
- ii) 16 mm film projector
- iii) Three four good films on leprosy

- iv) Slide projector with two three sets of slides
- v) Tape recorder with cassettes on leprosy
- vi) Flash cards Photo album
- viii) Microphonic set and accessories
- ix) Mobile exhibitions in 2-3 different sets.
- x) Equipment for puppet shows
- xi) Stencils for writing wall posters
- xii) Matter for posters, cinema slides
- xiii) Booklet for leprosy patients

On the basis of above, the quantity of material of education can be worked as also the budget necessary if this is approved.

On Software

Stress must be placed on the introduction of expert software in health education training. Communication and Education professionals should be involved in developing specific package for training programmes that improve the quality of delivery, messages and style of presentation of health educations.

Moreover, in the development of such software emphasis must be laid to use criteria of what can be assimilated in the culture system-such as concepts and ideas that are regionally meaningful.

In Health Education Research

The Shortcomings:

Often, health education has been found to be carried out as a one-way process. The rationale behind implementing health education as an exchange of communication of two-way process involving feed-back analysis though developed in the methodology of the earlier programme, has not been so effective. The system of statistical reports generation in the programme has not given much scope for getting a thorough evaluation of the health education practices or the quality of health education or its various influences. This discrepancy ought to be changed by proper research techniques in Health Education, as stressed by the Post-Congress Workshop. (1984: Wardha).

Action Suggested:

In addition to the overall social science research, specific research would have to be done in the evaluation of the methods and tools of health education used for leprosy control work for community participation.

Other areas of health education research necessarily include:

1. The study of messages absorbed by people and their duration.
2. Effectiveness of communication under various parameters—literacy level, prevalence of deformity rates, etc.
3. Viability of health education methods to suit new treatment regimens such as MDT.
4. Impact of school surveys on community.
5. Relative effectiveness of using various social groups for creating awareness in the community.
6. Motivation and perception of leprosy workers towards leprosy and its impact on the effectiveness of health education.

In Social Science Areas**The Shortcomings:**

At present, the resources and data available to understand the social aspects about the disease are abysmally low. There have been very little studies done to analyse this side of the problem. However, time and again, it has been pointed out that to solve a national health problem with such gigantic social stigma and psychological overtones, an

in-depth study in these areas is very vital.

Barring a few experiments done by a voluntary agency or another, there exists a gross shortage of social science research data.

Action Suggested:

Workshops on social science research should be given utmost priority, as equal to health education and medical services, and these workshops must be left to be organised by competent Indian and International agencies working in the field.

Up-to-date research techniques and tools in social science, behaviour psychology, and motivational aspects as well as the economic influences ought to be utilised to create a good data base.

Setting up of social science research Centres, on the lines taken up by GMLF (see chapter following) should be emphasised for many other agencies. Wherever such facilities cannot be set up, voluntary agencies as well as Government/Educational/Training Institutions must be instructed to draw from this existing data bank, and improve their system of operations.

Mass Awareness, Health Education and Community Participation promulgators should be familiarised with such social science approaches and research-based applications, for overall impact and effectiveness of their activities.

How To Make The Implementation of Health Education More Effective?

All efforts of scientifically re-organising and up-dating health education programmes would be in vain if the actual implementation of the subject falls short in methodology or application procedures on the field.

To avoid any such predicament one technique proposed is the job chart for leprosy health education workers which has been re-cast to create better results.

A format of the job chart for leprosy workers is illustrated below:

Job Chart For Leprosy Workers Para Medical Workers:

The Para Medical Workers will cover the following groups for health education.

1. Villagers in general.
2. Local physicians/health staff.
3. Social workers.
4. Youth groups.
5. Women's groups.

During his visits to every village, he will make more individual contacts with at least one leading person from any of the above groups.

He will organise and address at least four groups meetings every months, and talk to VHGs, ANMs, trained and local dais, anganwadi workers, youth workers, teachers etc.

He will make effort to cover every village once a year.

On every clinic day, he will talk with at least two patients about leprosy, regularity, care of the eyes, hands and feet.

Mobile exhibitions will be arranged at least once in a month.

He will carry flash cards/flip book with him in all his duties and will discuss them with all members of the family.

He will arrange, with the help of local youths, the following.

- * Wall slogans.
- * Wall paintings-- in at least two prominent places.
- * Bill boards, posters in shops, schools, offices, panchayat buildings, and places of worship.

He will observe leprosy week during which, besides usual health education programmes, he will arrange sale of leprosy seals and also essay competitions for students.

He will motivate and help other local bodies to organise leprosy week.

He will maintain proper and accurate record of health education and activities and submit reports, in approved format, to MO/NMS.

Urban Leprosy Worker

The following groups in urban localities will be covered by this category of workers:

- * General public.
- * Local physicians/health workers.
- * Heads of the institutions, employers.
- * Workers in offices and factories.
- * School teachers

- Social groups (Lions Club, Rotary Club, Bar Association, Press Association etc.)
- Women's groups.

He will contact and talk on leprosy with at least one leading person every day.

He will organise:

- One group meeting per week.
- One exhibition per month.

He will contact doctors and arrange for refresher courses for them twice in a year.

On clinic days, he will speak at least with two patients about leprosy, regularity, and care of hands, feet, eyes and nose.

He will carry flash cards/flip book with him in all his duties and will discuss them with all members of the families.

He will arrange with the help of leaders, youth groups, etc. the following

- Wall slogans.
- Wall paintings in at least two prominent places,
- Bill-boards in shops, schools, offices, gram, panchayat building, places of workshop.
- Exhibition of slides on leprosy by rotation in Cinema houses all the year round and during leprosy week, on every day in every cinema house.

Non-Medical Supervisor:

The non-medical supervisor should be charged with the special responsibility of helping para-medical workers under him to do health education systematically and to supervise it. His duties will include

- Supervise the work of the para medical workers by attending at least one health education programme conducted by each worker once a month.
- Discuss with the workers about improvements in the delivery and also in demonstrations, whenever necessary.
- Ensure that the health education activities are conducted as planned--in

the ATPs of the para medical workers.

- Ensure that the use of flash cards/flipbooks, pamphlets, slides etc are properly utilised by the para medical workers and health education is done on clinic days.
- Make available to the para medical workers, with advance planning and by rotation, the health education materials and aids which are available with him.
- Ensure that proper and accurate records of health education activities are maintained by the para medical workers.
- Independently undertake in his headquarters, all activities, which a para medical worker is expected to carry out with selected educated groups.
- Maintain his own records of the health education activity properly and accurately and file-in a comprehensive report, of the work of the para medical worker to the District Health Education Officer.

Apart from the above he will be particularly responsible in understanding measures and programmes for involvement of medical people both in health services and in private practice. In this activity he shall be expected to:

- Organise refresher courses for private medical practitioners and arrange the leprologists to address them.
- Extend help in organising seminars/workshops on leprosy.
- Organise workshops for doctors in services.
- Conduct and address programmes for the intelligent and affluent influential senior citizens.
- Extend help and support to voluntary leprosy institutions, if any in his area, in health education--through supply of materials and aids.
- Arrange programmes at his headquarters in leprosy.
- Make available special health education

aids which are with him to field units by rotation once a year.

- Verify that the records of health education activities are properly and adequately maintained by the workers.
- Prepare a consolidated report of health education activities in his District for onward submission to State Leprosy Officer.
- Meetings will also be organised by him involving field workers, collected at two or three places in the District to discuss the problems and to guide them about doing health education effectively.
- Evaluation of the effects of health education will also be done by him once a year.

District Health Education Officer.

The District Health Education Officer will be responsible for the health education activity in the whole district conducted by all leprosy workers and will also be responsible to motivate and involve non-leprosy institutions and groups in leprosy health education.

- He will be incharge of the Mobile Health Education Unit and will organise programmes in the entire district.
- He will undertake tour for not less than twelve days a month.
- He will directly supervise the Health Education part of NMS's duties and will take steps to see that:
- Health education activity is carried out properly by all categories of leprosy workers by being present in the programmes.
- Targets of health education laid down for para medical workers, urban workers and NMS are achieved.
- Adequate stocks of health education materials are available and supplied to field workers.
- Budget for health education activity is properly and fully utilised.

Medical Officer/District Leprosy Officer/ Zonal Leprosy Officer will:

- Hold overall responsibility for implementation of Health Education Programme in the District.
- Co-ordinate in the Health Education activities with other Health Education programme in the District.
- Rapport with District Collector/other District Officers/Voluntary agencies for the successful implementation of the programme.
- Organise polymedical skin check up camps.
- Coordinate with Lions/Rotary/Jaycees/Social Welfare Organisations.
- Publish write ups in Press, Talks in Radio, T.V. etc.
- Conduct classes to Nurses, ANM, PMW trainees
- Plan/organise Health Education activities in the district
- Supervise/Guide Health Education Workers, NWS, PMW in implementing Health Education
- Provide budget, purchase, repair, maintain Health Education tools, equipment
- Get Health Education Materials printed by Government/Voluntary Agencies
- Address teachers association/IMA.
- Celebrate Anti-Leprosy Day at the District/Unit level.

Production Of Health Education Materials – Another Priority For Effectiveness

As brought out in the Mass Awareness Chapter of this Plan, health education materials for leprosy is another area that needs to be strengthened. Since no good education activity can take place without the educators being equipped with the right quality and quantity of materials the Master Plan puts the creation of those materials in a better perspective.

In retrospect, it can be seen that the development of Health Education materials for the NLEP has been by and large insufficient and amateurish. Only a few Indian agencies have produced good material.

To enable the production and procurement of effective Health Education software and hardware the following criteria is suggested:-

Materials will be created on the basis of:-

- * The target group which a worker would handle.
- * The objective of health education to that group.
- * The media required to reach that groups' comprehension

Thus, specific classification of Health Education materials would be necessary in terms of the type of hardware to be used, the software, and the category of the worker who would use them.

Also to maintain the cohesiveness of health education delivery the Screening Committee (suggested under Mass Awareness chapter), would take responsibility in the actual production of materials—for each region, under the guidelines outlined.

There is an immediate necessity to promote more agencies to produce health education materials.

A Primary Health Care Model For Better Health Education

In an information paper prepared for the Regional Committee's discussions on the 'Control and Prevention of Leprosy in the context of the Primary Health Care', the WHO presents an useful model for the application of the health education delivery system.

The document states, "The key factor in the Primary Health Care approach is its focus on the 'consumers' of the health care, delivery system...(in) education concerning prevailing health problems and the methods of preventing and controlling them. Considerable attention should be given to the need of health promotion at people's homes. In the area of leprosy control, this includes ensuring patient compliances, daily treatment and surveillance of the contacts to detect the disease at its earliest manifestation".

Listing the broad categories of the activities, the model outlines:

- * early recognition of suspected leprosy patients, appropriate referral and treatment.
- * surveillance of high risk groups e.g. contacts schools etc.
- * interruption of transmission of the disease.

In an elaboration of the approach, the relevant tasks and support activities required at various levels are also indicated. An extract follows:

PHC ELEMENT NO. (6): PREVENTION AND CONTROL OF LEPROSY

Activities	Level	Tasks involved	Person (s) responsible	Competence and knowledge required	Supplies and equipment	Logistic support	Community support
1. Early recognition of suspected leprosy cases and their referral	1.1 Home	(a) Recognition of early symptoms of leprosy particularly hypopigmented patches, and loss of sensation	Individual family members, father/mother	Knowledge of symptoms of leprosy and its consequences	Suitable information material like pamphlets, etc.	Procurement of drugs and regular supply to the patients	Community-generated support, e.g., health committee and volunteers
		(b) Seeking confirmation of diagnosis and treatment		Knowledge of availability and location of health facility			Support and health education in schools and by voluntary agencies
		(c) As above	Village health volunteer	Ability to identify symptoms of leprosy and its complications	As above Check-list and/or manual of his tasks	Access to refresher training Storage of drugs and other supplies	Facilities for CHWs Community cooperation and acceptance Support from community development committees or similar bodies
		(d) Directing patients to referral facility for confirmation of diagnosis		Knowledge of referral facilities			
		(e) Absentee follow-up		Basic training in health education Ability to communicate with supervisory level		Spot map of villages and houses	Identification, selection and training of CHWs in cooperation with health authorities
	1.2 First health facility	(a)-(e) in 1.1 above (f) Confirmation of diagnosis (g) Taking skin scopic and microscopic examination	Multipurpose workers, nurses, medical assistants physicians	Adequate theoretical knowledge and practical skills about leprosy with basic elements in epidemiology treatment and methods of control of leprosy	Kit with recording forms, stationery pin and feather for testing sensory loss. Essential drugs Manuals	Records Stores Referral system Transport for home visits	Assistance with Transport facilities Assistance with land and building facilities Supervision Support to training of community members and CHWs

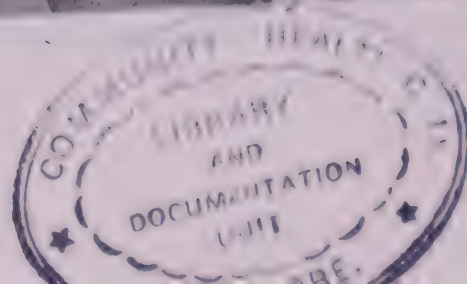
Activities	Level	Tasks involved	Person (s) responsible	Competence and knowledge required	Supplies and equipment	Logistic support	Community support
		Record-keeping and reporting of leprosy morbidity		Clinical examination of patients testing for sensation and thickening of nerves	Laboratory equipment and supplies	Spot map of villages	Appropriate communication system, e.g., public transportation telecommunication etc.
		(i) Supervision of CHWs					
		(j) Training community members and CHW whenever possible			Transport facilities for supervision		
	1.3 First referral level	(a) Adequate management of complications	Nurses Physicians	Adequate knowledge and practical skills of the clinical and preventive aspects of leprosy	Manuals Laboratory supplies	Stationery Management of supplies Stores	Public transport Appropriate communication system, e.g., public transportation tele-communication
		(b) Supervision and continuing training of village health volunteers		Ability to assist in the diagnosis of difficult cases Knowledge of the national leprosy control strategies		Transport	
2 Treatment	2.1 Home	(a) Motivate patient to take self-administered drugs daily	Individual family members, father/mother	Knowledge of health and social consequences of the disease	Suitable information material like pamphlets	Facilities for health education	Community cooperation Health education at community level
		(b) Motivate patient to attend health facility monthly for supervised administration of drugs		Knowledge of transmission Knowledge of personal hygiene Knowledge of elementary oil massage and exercises			
		(c) Watch for complications					
		(d) Supervise simple physiotherapy e.g. oil massage exercises					
		(e) Promote personal hygiene within the family to prevent transmission					

Activities	Level	Tasks involved	Person (s) responsible	Competence and knowledge required	Supplies and equipment	Logistic support	Community support
		As above from (a) to (e)	(a) Village health volunteer	As above	Kit pin and feather with stationery	Facilities for health education	As above
		(f) Home visits		Knowledge of drug administration and complications	Relevant information material, e.g., pamphlets, etc.	Transport for home visits	Facilities for housing, etc.
		(g) Treatment delivery in special situations		Recording and Reporting			Support of village health committee
		(h) Supervision of home tasks				Inventory/spot map of villages and houses	
		(i) Health education					
		(j) Referral to health facility if complications occur					
	2.2 First health facility	As above in 2.1	Multipurpose worker/paramedical (leprosy) nurse/midwife, medical assistants physicians	As above	Adequate drugs	Facilities for health education	Provision of local facilities for training of CHWs
		Treatment and drug distribution		Knowledge of epidemiology and treatment of leprosy including its complications	Relevant information material like pamphlets, etc.	Supervision	Transport
		Treatment of complications			Slide projectors and other audio-visual equipment for health education	Manuals	
		Referral for admission, if necessary		Capability of participating in training of CHWs		Preparation of training for CHWs	Transport facilities
		Maintaining adequate stock of drugs			Material for equipment and training		
				Group health educational activities in the community		Inventory/mapping of village	
		Recording and reporting system, compilation of data and analysis			Facilities for transporting patient to first referral level		
		Supervision of home task responsibilities					

Activities	Level	Tasks involved	Person (s) responsible	Competence and knowledge required	Supplies and equipment	Logistic support	Community support
	2.3 First referral facility	<p>Treatment of complications</p> <p>Admission, if necessary</p> <p>Laboratory investigation if side-side effects occur</p> <p>Supply of drug and reagents to periphery</p> <p>Supervision of CHWs and first health facility</p> <p>Training of CHWs, health workers and first health facility personnel</p> <p>Epidemiological and operational assessment</p>	Nurses physicians	<p>As above in 2.2</p> <p>Knowledge of all aspects of leprosy and national control strategies</p> <p>planning supervision and evaluation capabilities</p> <p>Training</p>	<p>As above in 2.2</p> <p>Laboratory equipment and facilities for investigations</p>	<p>Facilities for health education</p> <p>Participation in the training of CHWs and first health facility personnel</p> <p>Supervision</p> <p>Transport and communication facilities</p>	<p>Appropriate communications systems, e.g. public transportation, etc.</p>
3. Surveillance of high risk groups, e.g., contacts, school children etc.	3.1 Home	<p>(a) Awareness of early signs of leprosy</p> <p>(b) Undertaking preventive measures by good personal hygiene</p> <p>(c) Acceptance and cooperation of all family members to undergo clinical examination</p>	Individual family members	<p>Knowledge of health and social consequences of leprosy</p> <p>Knowledge of transmission of leprosy</p>	Suitable information material like pamphlets, etc.	<p>Facilities for health education</p> <p>Regular provision of to patients to reduce infectivity</p>	<p>Community generated support e.g., health committees and volunteers</p> <p>Support and health education in schools and religious institutions, etc.</p>
		<p>(a) Maintenance of contact register and annual examination of family members</p> <p>(b) Home visits</p>	Village health volunteer	<p>Identification of high risk groups, e.g., contacts, school children</p> <p>Knowledge of transmission of leprosy</p>	<p>Kit with pin and feather for testing loss of sensation and stationery</p>	<p>Facilities for health education</p> <p>Spot map of villages and households</p>	<p>Facilities for village health volunteer (housing, etc.)</p>

Activities	Level	Tasks involved	Person (s) responsible	Competence and knowledge required	Supplies and equipment	Logistic support	Community support
		(c) Health education on personal hygiene (d) Ensuring regular treatment of index case to reduce infectivity (e) School surveys		Ability to suspect early signs and symptoms of leprosy			
	3.2 First health facility	As in 3.1 above Confirmation of diagnosis Taking skin smears and microscopic examination Record-keeping and reporting of leprosy morbidity Supervision of CHWs epidemiological studies to identify high risk group	Multipurpose worker, nurses medical assistants physicians	Adequate theoretical knowledge and practical skill about leprosy with basic elements in epidemiology Treatment and methods of control of leprosy Clinical examination of patients testing for sensation and thickening of nerves	Kit with recording forms, stationery, pin and feather. for testing sensory loss Essential drugs treatment and Manuals Laboratory equipment and supplies Transport facilities for supervision	Records Stores Referral system Supervision Transport for home visits Spot map of villages	Assistance with transport facilities Assistance with land and building facilities Support to training of selected members and CHWs Appropriate communication system e.g. Public transportation tele-communication etc
	3.3 First referral level	(a) Epidemiological and operational evaluation (b) Promotion of health education (c) Supervision of lower levels.	Public health medical officer	As above in 3.2 Methods of leprosy control	Facilities for health education Facility for evaluation	Transport facilities	Intersectoral co-ordination and cooperation with school health authorities, factory medical officers, etc.

COMMUNITY PARTICIPATION



What Does Community Participation Mean?

How Can It Be Made More Effective?

Community Participation assumes a very specific meaning in the control of leprosy. Based largely on health education and mass awareness, its goal must be, as Prof. George M. Foster of the Department of Anthropology, University of California, put it, "to win the sympathy and tolerance for patients, and to lead a correct understanding of the nature of leprosy itself, particularly that it is a relatively limited threat to the vast majority of community members."

The real objective of community participation is to make the community conscious about a specific problem so that the community will find out its own ways to solve it. In the context of the leprosy problem, the effort should be to make the people aware that leprosy is everyone's concern, that it is a common, curable disease and the essential requirement is to treat anyone suffering from leprosy with sympathy so that he does not feel either ashamed or afraid, and does not conceal the disease, continues to stay at home, and carries on his job/works and takes regular treatment until completely cured.

Thus, the objectives of Community Participation are many and inter-related. As expressed by Prof. R. K. Mutatkar in his keynote address at the XII International Leprosy Congress, "Community participation, refers to (a) involvement of community in utilisation of services, and (b) participation in decision making. The objectives of community participation are (a) to increase acceptability of leprosy control (b) to increase effectiveness of leprosy control and (c) to increase cost effectiveness. Indicators of success could refer to (a) decrease in deformity rate, (b) voluntary reporting and (c) utilisation of services."

In detail, community participation refers to involvement of community in case detection, case holding, regularity of treatment and rehabilitation of patients.

Action has to be initiated by opinion leaders and lay persons to be followed up by statutory, informal, traditional local bodies at the village and the district level. The tasks to be accomplished are :

1. Voluntary Reporting
2. Organising health education programmes.
3. Making civic facilities like water places, barber, washerman etc. available to Leprosy patients.
4. Supply of drugs.
5. Marriage counselling in cases of threatened divorce on account of leprosy.
6. Prevention of harassment of women and children.
7. Prevention of grabbing land from leprosy patients.
8. Acceptance of patients released, from hospitals and leprosoria by the community.
9. Occupational rehabilitation.
10. Provision of socially acceptable and viable places for leprosy clinics and residential accommodation for leprosy workers.
11. Formation of special health or leprosy control committees at the local level.

Which Are The Group That Encourage Community Participation?

To accomplish a national scale action generation for a problem such as leprosy

eradication, a wide cross section of influential groups need to be motivated to initiate the action. The following are some of these groups:

Medical Profession

This is the most vital group that can influence people in health related matters.

In this group, the coverage must be made so adequate as to include all categories of medical practitioners such as General/Private Doctors, Government Doctors, Ayurvedic/Homeopathic/Unani and similar Traditional Medical Practitioners.

Since this group is directly associated with health and disease matters, the motivation attempts towards them ought to be made significantly powerful, to elicit participation in the Programme in a substantial way.

Anganwadi Workers

The Anganwadi Workers group, is a substantially influential group especially in the upcountry rural areas. Spreading the message of control of leprosy must be inserted in their regular social work of child development and health education. The primary health care approach practiced at this level, is an effective tool to drive home the salient features of leprosy control to the village level audience especially the female class. They must be motivated to carry flash cards, picture stories, as aids to their communication.

Gram Sevaks/Patwaris/Village Leaders

These are yet another social group that needs to be mobilised in support of the NLEP. Being respected and looked up to for counselling, advices in various village matters, their opinions and advices would make considerable impact among the target groups for moulding behaviours.

Religious Leaders

Massive following for religious leaders of various regions is an indispensable part of our country's cultural practices. Orientation to the true facts of leprosy cure and its social aspects ought to be made clear to this group in a convincing way, so that they in turn, influence, the followers.

While religious superstition is a main drawback with regard to the disease's social overtones the achievement of sensible thinking

could be enhanced with (a) visible proof of scientific cure (b) discussions, debates and forms with religious leaders (c) conceptual integration of the overall objectives of health practice and benefits etc.

Social Welfare Clubs

Social welfare clubs like Rotary, Lions, Jaycees, Giants, Round Table, etc. ought to be mobilised in contributing to the cause through (a) adoption of villages in leprosy endemic areas, (b) promoting the promulgation of the message through sponsored publicity programmes (c) holding discussions/talks on leprosy control etc.

Railways/Industrial Townships

Townships and colonies of several big corporations, like BHEL, SAIL, ISRO, BEL and similar organisations as well as Railway Colonies, Electricity Boards, University Campuses, etc are other targets where community participation programmes can be encouraged to support NLEP.

NCC Cadets/Bharat Scouts & Guides/Youth Groups

Involvement of large and widespread groups such as NCC Cadets/NSS Members/YMCA/YWCA, and similar youth groups in the country would be a great step towards taking the NLEP activities to far-reaching results.

Successful Experiments In Community Participation:

Why Not A National-Scale Adoption?

Leading voluntary agencies Indian and International are agreed that certain nuances in Community Participation exercise significant influence on Community behaviour and opinion.

A unique experiment conducted at Balarampur in West Bengal, as also the experiment carried out through Anganwadi workers where people were motivated to "think and act for themselves"- serve as a pointer to the manner in which people could be motivated on a national-scale to participate in a constructive project.

An excerpt regarding these experiments is given in Appendix 7.

SCREENING, RESEARCH COORDINATION AND EVALUATION INFRASTRUCTURE

A systematic result-orientation of the NLEP calls for several areas of activity which need to be brought under a cohesive and comprehensive umbrella.

Able complementing the recommendations under the 3-pronged strategy—Mass Awareness, Health Education and Community Participation—the Master Plan also puts forth the following networking programme to cover such vital areas as Screening & Quality Control of the delivery; setting up of a Social Science Research base; Coordination of the implementation of the Health Education; and the Evaluation and Documentation methodology.

A Screening Committee

It is a fact that leprosy has been projected with inadequate intensity during the Programme period. What is even more disappointing is that there have been occasions when the disease and its characteristics were displayed with repulsive or negative or meaningless appeals by many an agency involved.

That's not all. In a large number of health education material the style and content have been found to be incorrect or unappealing.

The underlying cause for these discrepancies has been identified as a basic lack of understanding of the subject of leprosy and health education, by the promoters of these materials. While due credit ought to be given to the Press for exposing the leprosy problem through several articles, features, coverages etc in a majority of these attempts, discrepancies of wrong projections have crept in.

The Mass Media experts seldom have had the opportunity to concentrate on the problem, assimilate the communication needs and come

out with effective portrayals in a scientific nature. Nor have the mass communication professionals been entrained so far, into thinking in this direction. This kind of misinterpretation or wrong projection, mostly unintentional, is best evident in instances like the use of the word 'leper' in a large number of articles by the Press, although it was removed from common parlance even as early as 1940 at an International Leprosy Congress in Malta. In another example, in a regional film released on national network, a leprosy patient is shown as being cured in an instant, miraculously, at the touch of a divine power and in yet, another case, a scene in a film projects a doctor diagnosing leprosy after looking at the patients' X-ray.

While accepting the necessity of avoiding misleading representations cited above, due care should be taken to ensure that even in presenting reality, the positive aspect should be portrayed with emphasis—so as to create a more sympathetic understanding of leprosy.

It must be appreciated that presentation of negative aspect and unintentional but wrong appeals for the sake of 'effect'—attributed to 'artistic license'—would tend to mislead the audience.

In a problem like leprosy with its psycho-medical overtones, which makes it all the more complex, we cannot afford the liberty of such portrayals for only 'effect's-sake'.

There are many other communication software that projected the disease in the correct perspective. For instance, a feature film recently produced by a voluntary agency and scheduled for national exhibition brings out the real life story of an otherwise healthy-looking average man who is motivated to take medical advice for the patches

on his skin, and is thus detected as a leprosy patient at the first signs of the disease. The film goes on to show how he continues medical treatment and is happily relieved of the disease totally resulting in a very positive picture of timely advice, complete cure and perfect re-adjustment into the mainstream of life.

Social Science Research Infrastructure

So far, there were no concrete efforts for social science research in leprosy except, some small studies undertaken on conventional lines. There is not only immense scope for improvement but also an urgent necessity to do it on scientific lines.

What is needed is a systematic and modern methodology involving more scientific tools and techniques for creating better data base and evaluation.

The need for establishing an agency which can initiate such researches and also help all those social science and leprosy bodies interested to take up such studies was recommended by the National Seminar on Social Aspects of Leprosy held at the Tata Institute of Social Sciences Bombay, in Nov. 1982 and the pre-Congress Workshop on Social Aspects held at New Delhi in Feb. 1984. Both these meetings identified the Gandhi Memorial Leprosy Foundation as the proper agency to take a lead in this respect.

The Gandhi Memorial Leprosy Foundation has initiated the establishment of a Centre for Social Science Research at Wardha, Maharashtra. The Centre aims:

1. to identify areas for social research in leprosy.
2. to identify institutions and scholars who can undertake researches.
3. to offer guidance to the institutions/scholars in preparing research projects, help them in monitoring the projects and preparation of reports.
4. to organise, if necessary, short term training courses in research methodology,

and hold seminars/workshops, and

5. to develop documentation on social aspects of leprosy.

The Centre would explore the following areas of research and documentation:-

a. Operational Research

- The application and effects of health education as a single factor in case detection.
- The extent of survey per se as a single tool of health education in detection of cases.
- The effectiveness of communication in changing attitudes and practices.
- Inter-media, inter-message and inter-process studies in communications.
- Management studies of vertical survey and treatment programmes vis-a-vis integrated approaches.

b. Basic Research

- Studies in social stigma—its cause, its affectations and opinions on it by different social groups.
- Present knowledge of the groups regarding causation, transmission, treatment and cure of the disease.

c. Supplementary Research

- Decision making processes and their effects in health matters at local community level and family.
- Health beliefs, practices and also health aspirations of the groups.

The above is only an indication of the scope of the Centre's proposed activities. Equipped with the latest in hardware—including such infrastructure as microcomputer, and other equipment, the Centre will delve into the entire gamut of social science aspects of leprosy and health education - to produce an infallible

reservoir of up-to-date and scientific data and methodologies for supplementing the leprosy control programme in the country.

With this intensive background and facilities available, it is recommended that the Government and other concerned agencies should encourage voluntary leprosy organisations as well as institutions engaged in education, communications, sociology, anthropology, social work, management of health etc., to identify and take up research activities in these fields.

Institutions like ICMR, ICSSR, Ministries of Social Welfare, Education etc. should be encouraged to provide financial aids/grants for such research study and projects.

It must also be noted that the Foundation's Social Science Research base may be pointed out to be amply utilised by any interested voluntary organisation or institution engaged in the field of leprosy and health education to conduct experiments in the field and/or to set up their research facilities for social science studies in leprosy eradication and health education.

Coordinating Agency

In order to keep a strict vigil on the quality of the delivery of health education and mass awareness programmes, the formation of a coordinating agency is mooted.

It is true that in leprosy eradication, a number of apex bodies and committees are already in existence at the Centre/Regional levels. Most of the bodies are largely concerned with the formation of the policies or the coordination of the more concrete and easier tasks of the programme and as pointed out, have given less stress to health education.

It is pertinent at this stage to take a look at the activities which some of the established voluntary agencies have carried out in this field.

Due to its independent existence and voluntary interests, this sector has made substantial in-roads into several areas of leprosy control and health education hitherto unexplored.

Hence it would be in the best interest of the Programme that a well-knit coordination committee/agency is organised—comprising experts in education and communications from the voluntary sector.

The agency must be drawn up of experts from institutions that have undertaken resourceful and result oriented activities in leprosy control in areas like epidemiological studies, production of health education material, social science research, communication techniques and have made noticeable contribution to the application methods of NLEP.

While the monitoring of the entire gamut of activities in the NLEP would be much beyond the scope of the coordination committee, several areas in health education could be put within its scope: For instance:

1. Development and implementation of Mass Awareness strategy in leprosy control—including the setting up of consortium of advertising agencies/practitioners.

2. Development and implementation of effective health education material.
3. Development and operation of a Social Science Research base for leprosy—and coordinating the projects in this direction.
4. Making available the results and findings in leprosy control and recommending them for national scale adoption in NLEP.

Evaluation

Evaluation may be defined as the selection, collection and presentation of information for making decision in the light of a value system and already defined objectives.

Basically, “evaluation raises the much more difficult questions (than information)”, says Dr. W. Felton Ross, American Leprosy Mission, USA, in his lecture material for the International Workshop on Leprosy Control in Asia. He continues, “the questions evaluation puts forth are:—

Was it well done?

Was it worth doing?

Could it have been done better?

What lessons can be learned from doing it?

From whose point of view was it worth doing?

What impact does the programme have on people as people?

Not only did the project succeed or fail to reach it's objective, but why did it succeed or how did it fail?”

Scientific evaluation progress for leprosy control activities should involve (a) Context Evaluation—the evaluation before the program begins, to determine objectives, strategy and resources (b) Process Evaluation—the evaluation during the program to enable judgements to be made in the light of the progress, and (c) Output Evaluation—the evaluation of the results in the light of the objectives.

There is no end to the information that could be collected but not all of it is useful. One of the frustrations of leprosy work today is that a great deal of devoted work is being done to collect the information that is not used. Or vice versa.

According to modern theories of practices, there are five principles which help make value judgement:

- * **Relevance:** The collecting of information that is useful for decision making.
- * **Commensurate results:** The cost-efficiency of evaluation benefits, while there are no quantifiable guidelines in this area it is reckoned that the investment in evaluation should lie between 1% and 5% of overall costs.
- * **Key result areas:** The key result area in leprosy control is the patient's homes. Key result area is the area of particular attention during evaluation.
- * **Accuracy:** A little accurate data is far more reliable than to maintain a mountain of unreliable data. Inaccurate information is dangerous.
- * **Coverage:** This means the important areas to be covered for evaluation— determined by context and objectives, strategies, control of activities and assessment of results.

With regard to the NLEP, evaluation activities must be determined taking into consideration the factors in the following areas:

Objectives Of Evaluation

1. To monitor whether the main objectives are achieved or not.
2. To assess the strong and weak links in the implementation and suggest corrective measures.
3. To evaluate operational aspects and suggest corrective measures in the areas, if any, and
4. To assess the performance of staff in the duties assigned and the impact of the programme on the community.

Evaluation Of Staff Programme

This is an important part of supervision at different levels. The performance of the field workers in relation to their achievement of target, utilisation of various media, and the immediate impact of the efforts need to be evaluated.

Impact Evaluation At Grass Root Level

Records of specific events and actions resulting from health education activities in the community, if properly maintained by para medical workers, anganwadi workers, and similar operators at grass root level can help assess the immediate and direct impact of the efforts.

It is in this context that such experiments done by Indian and International voluntary agencies in ascertaining such information, gains considerable attention for national scale adoption.

Parameters Of Evaluation

The effect of various health education programmes on the community can be assessed by:—

1. Voluntary reporting of individuals for suspected signs of leprosy.
2. Number of cases detected from individuals reporting with suspicious signs.
3. The stage at which disease was suspected by the people for reporting.
4. The number of leprosy patients employed in organisations, with the knowledge that the person is a patient.
5. The number of general practitioners who take up diagnosis/treatment in their clinics.
6. Instances of community support to leprosy patients in instances of social harrassment.
7. Reduction rate in re-habilitation of leprosy afflicted persons from family units, social groups, vocations etc.

While the above areas of research possibilities have been identified, it is felt that given the right scientific inspection, a more exhaustive list could be prepared. The imminent need hence is to seek more areas under more parameters for social science research.

Mechanism For Evaluation

The present mechanism for evaluation of health education is in the form of evaluation teams at State level. Some States have already appointed these teams and are on this job.

It is advised that, the teams may be asked to consult experts with social science background or in health education, while carrying out this evaluation and thus improve the quality of findings through scientific, social science research methodology like interviews, case studies etc.

It is pertinent, at this stage, to take note of the review and conclusion done by Dr. K.C. Das, as far as the Indian Leprosy control work is concerned.

Identifying the problems encountered, he has highlighted the following areas that need attention:

Possible Remedies

- a. Compilation of large quantities of information needs separate cell with modern methods of computer system. Separate trained staff are needed for that, under guidance of statisticians.
- b. Large number of forms followed in collection of data need standardisation and if possible, limited to only scientific control data. The styles of records used by different units of Government and voluntary agencies, ought to be standardised.
- c. Regular monthly feedback is essential.
- d. Forms are to be devised for district-wise campaign.
- e. Long-term trends of the disease in each country should be done through model centres.
- f. Funds must be supplemented for printing and production of evaluation records at unit levels.
- g. The shortage of computer professionals, statistical assistants and investigators at the Unit, District, State and Central level ought to be rectified.

Documentation

All the efforts to the scientific orientation of the programme can lead to little result unless documentation also follows through in its true spirit and practice.

Health education records ought to incorporate the following suggestions:

- * Records should be adequate for qualitative and quantitative expression of work.
There must be scope for recording individual quantitative observations.
They must be useful for evaluation.
- * They must be designed in such a way that minimum burden is put

on the operating staff in maintaining it.

- * Two types of records are suggested:
 1. Quantitative Records: Consisting of advance tour programmes of all categories of workers, Daily Diary, Registers (for non-medical assistant/leprosy technicians), Monthly Register (for non-medical assistants), Records of village work.
 2. Qualitative Records.
Consisting of day-to-day observations in detail about instances indicating favourable attitude/behaviour noticed in society; and target achievement records.

The design of the records should be such that uniformity is maintained in the information collected from all States.

ROLE OF VOLUNTARY AGENCIES NETWORK

Health education in leprosy, having been dove-tailed into the National Leprosy Eradication Programme has been consistently viewed as primarily a responsibility of workers in Government centres.

However, a strong voluntary sector in leprosy field is supporting and collaborating with the Government, in this activity. Hence the suggestions and recommendations mentioned this Master Plan also have application to these voluntary leprosy institutions in the respective areas where they are functioning.

On recapitulation of the health education done so far, it comes to light that the voluntary agencies, by virtue their motivation and manner of functioning, can be significantly helpful in:

1. Extending their services either in the immediately surrounding areas covered by Government centres or at State level to help the Government workers in health education activities. This could be done in addition to the work taken up individually by these agencies.
2. By mobilising participation of different influential groups in the society.
3. In the production of health education aids and materials suitable to the regional/local needs and also in making them available to Governmental centres.
4. In feeding the mass media with news, lectures, programmes etc. on leprosy control work and health education.

It must, however, be stressed that every voluntary leprosy institution will not be able and may not have the necessary expertise or resources, to undertake the different activities. Hence, one voluntary institution may take up only one activity in their own and/or surrounding districts while another institution

may take up one or more areas not only in their immediate vicinity but at the State level.

It would be immensely helpful for the NLEP, if the services of these voluntary leprosy institutions are utilised in the following patterns.

1. Identification of suitable voluntary institutions with expertise and resources for participation at (a) local (b) regional and (c) State levels. This identification can be done with the support of GMLF, TLM, and NLO.
2. Identification of the areas in which each of the institutions can participate.
3. Identification of the manner, area or programme for participation.
4. Motivating the respective State Governments to take help of these institutions.
5. Extending financial support to; and/or encouraging such supports to voluntary institutions for activities outside its own sphere of work.

AREAS OF CONTRIBUTION

Following are the areas where services of voluntary agencies can be availed of:

Running health education training centres:

There is only one training centre for health education techniques in India. It is urgently necessary to establish at least five more training centres. One or two State Governments may come forward to start such centres and some voluntary institutions can be approached to start a few. The Government should provide also for non recurring expenditure, equipment and grants for salary of the teaching staff.

In-service training of leprosy workers:

Voluntary agencies be motivated to depute their staff for in-service training of leprosy workers in their own or adjoining districts. For this, the Government may provide travel expenses and a per diem allowance for their workers.

Orientation for general health workers:

Orientation programmes, workshops, seminars etc. may be encouraged to be organised by voluntary agencies, for general health workers, with the same financial arrangement as suggested above.

Honorary Health Education Officers:

The appointment of Honorary Health Education Officer (Leprosy) on the lines done by Government of Maharashtra by the voluntary agencies is another contribution which the NLEP can benefit from. This is because, such persons are selected from the senior and experienced officers of voluntary institutions who can carry out the following functions.

- a. Give guidance to leprosy workers in health education.
- b. Contact district level health officers and discuss about health education programmes.
- c. Address special groups such as heads of institutions, IMA members, members of social service clubs (Rotary, Lions, Jaycees, Giants etc.) and such other groups.
- d. Carry out health education in teacher training institutions, medical and nursing institutions etc.

The State Governments can select three or four such Honorary Health Education Officers (Leprosy) for the whole State and allot areas for their work. The budget necessary for this will be provision for their travel and per diem allowance.

Motivation of General Practitioners

Voluntary institutions can make contact with local IMA branches and conduct

refresher courses for general medical practitioners. Such institutions with competent medical staff, can take up this activity in their own and surrounding districts. The Government can meet a part of the expenses for each refresher course conducted.

Mobilising community participation:

Voluntary institutions can motivate youths, NSS students, NCC cadets, ladies groups, social organisations in participating in leprosy programme through some simple, but vital activities such as (a) organising health education, (b) suspecting early cases, (c) assisting in case detection programme, (d) ensuring regularity of treatment, (e) preventing social harassment (f) actively intervening in the dis-employment of a leprosy patient or in preventing displacement of a leprosy patient, etc.

Production Of Health Education Material:

This subject has already been discussed. It can briefly be summarised as follows:—

- a. Suitable agencies be recognised who are doing or are willing to take up this activity.
- b. Defining the particular areas of aids and materials which each one will produce.
- c. Arranging for purchase of the material by the State Governments.

Research in Social Aspects

It is already mentioned that researches and studies in health education and social aspects of leprosy must be initiated through both voluntary leprosy institutions and social science bodies in the areas of case detection, case holding, health education, social stigma, rehabilitation, etc. The voluntary institutions should, with the help and guidance of GMLF's Centre for Social Science Research take up some of the studies.

Long Term Activities

The activities for the later stages of the

NLEP which voluntary institutions can undertake can be divided under two heads (1) activities in their respective areas of operation and (2) activities in a larger area to supplement the governmental efforts.

1. Within Own Area

The following activities may be outlined for voluntary agencies for their own area, district and in adjoining area:

a. Own Activity

Intensive health education with all aids.

b. Help In Governmental Activity

1. Health education programmes in the Government covered areas.
2. Participation in training programmes at district level, for other health workers.
3. Lectures on leprosy in district level training centres for nurses, voluntary health workers etc.
4. Organising and participation in workshops, seminars in-service training, orientation programme etc.

c. Community Participation

1. Motivation of general/medical practitioners to diagnose and treat leprosy patients.
2. Motivation and help to non-leprosy voluntary agencies working in medical field to aid in leprosy work.
3. Motivation of social service clubs, youths, NSS, NCC and women's groups and in planning and conducting of leprosy programmes.
4. Deliver talks and feature programmes to nearby AIR stations.
5. Supply articles and news about leprosy events to the local press.
6. Organise mass publicity

through posters, hoardings, billboards, exhibitions, printed literature, etc. with donations from the public.

2. In A Larger Area

Voluntary agencies, with necessary expertise and experience, may be asked to take up one or more of the following programmes in their State, Region or National level:

(a) Production of material:

- i. Production of prototype of material and aids
- ii. Production on large scale and in regional language of the material based on the prototypes and their distribution.

(b) Training:

- i. Running health education training centres
- ii. Training in leprosy control
 - in Government /medical and health training centres
 - in medical colleges
 - for general medical practitioners
 - for workers of non-leprosy institutions.
- iii. Participation in training in health education
 - in-service training of trained leprosy workers.
 - in-service training of trained health staff
 - in-service training of general health educators.

(c) Health Education Activities:

- i. Running special health education units.
- ii. Conducting intensive education activities in their nearby areas.

iii. Providing services of their experienced workers as Honorary Health Education Officers, with State Government approval.

iv. Assisting leprosy workers of adjacent Government leprosy centres in some health education programmes.

v. Providing material for mass media (programmes for TV and AIR, news and articles for the press etc.)

(d) Mobilising Community Participation

i. Motivating general medical practitioners to diagnose and treat leprosy patients in their clinic/dispensaries.

ii. Motivating non-leprosy medical institutions to take up leprosy work along with their other activities.

iii. Motivating and involving groups of NSS, youths, women in health education and rehabilitation services.

iv. Motivating and involving social services clubs and agencies in leprosy programme.

(e) Social Science Research

Some of the voluntary agencies can take up research in Social Science areas,

particularly in the fields of case detection, case holding, health education, rehabilitation etc. This could be done with the help and guidance of GMLF's Social Science Research Centre.

Contribution by International Agencies

There are a number of International Leprosy Agencies some of whom are only extending financial assistance to voluntary leprosy institutions in India whereas some have agreements with the Government of India for participation in NLEP. Besides, the involvement of some agencies is restricted primarily to medical and research fields, whereas some are interested in almost all aspects of leprosy work.

It is recommended that the Government of India should have a dialogue with all the agencies to find out whether they can take up some activities envisaged under this Plan and also to find out the quantum of funds that can be mobilised through their resources. Another point to be discussed with them will be whether they will take up the activity themselves or extend support to those agencies who take them up.

Such a dialogue with all the international agencies should be started early.

THE PRE/BUDGETARY IMPLICATIONS

As mentioned in the Summary of this Master Plan, to work out a proper budget, it requires far more facts, figures and know-how and it would be appropriate to carry it out at the Central level.

In Dr. Swaminathan Committee Report under Chapter VI 3(d), a consortium of voluntary agencies was suggested along with the recommendations that a National Fund for Leprosy Eradication be set up.

While this recommendation is under consideration at the Central level, it would be significant to take into account the following suggestions, which such a consortium could implement in raising financial base for the programme. This could be in addition to the Central Budget and the said Leprosy Fund.

The methods of fund raising suggested are:

1. Fund collection from the Public by donations solicited through direct advertisement for the consortium agency.
2. Mobilisation by holding charity entertainment/cultural shows of plays, films, cultural events.
3. Fund generation by soliciting donations from the industrial sector.

4. Fund generation through other means like printing of seminars sale of leprosy seals, Health Education literature etc.

The fund collection drive through voluntary agencies supported by adequate concessions like tax exemption, etc., could result in mobilising substantial financial resources.

In conclusion it is stressed that with the approval of the consortium of voluntary agencies and the outline of these broad priorities, budget outlay of the Centre for the programme can be sufficiently augmented.

To implement the recommendations of the Master Plan, it would require considerable amount of financial outlay.

It is calculated that given the encouragement and acceleration to the activities in this Master Plan, it would not be a difficult task to motivate a number of agencies and sectors in the country to carry out the Programme, either on sponsorship basis or on lump sum contributions or in participatory methods, which do not drain the allotted budgets of the national exchequer.

APPENDIX I
EXTRACT FROM THE
REPORT OF THE WORKING
GROUP ON ERADICATION
OF LEPROSY CHAPTER V
(Dr SWAMINATHAN
COMMITTEE REPORT)

PAGE 41

MASS COMMUNICATION,
HEALTH EDUCATION AND
PEOPLE'S ACTION

The scientific and technical knowledge, delivery systems, public policies and environment in relation to leprosy need to be geared to meet the challenge of eradication of leprosy by mobilizing mass communication, health education and people's action. The main hurdle in achieving a breakthrough is to bring about a change in the knowledge, attitudes and practices of the society as a whole, and various target groups including the health personnel.

As leprosy is associated with social stigma arising out of fear, ignorance and superstitious beliefs handed down from generation to generation, for over 2000 years, and as our effort is to change the prejudices within a short span of 20 years, a mass communication and health education by saturated and sustained campaign should be launched. This should be done after a thorough preparation with adequate inputs including software and after setting up institutional bodies at the central, state and district levels.

Simultaneously with the launching of the programme, adequate infrastructure in terms of personnel, stockpiling, supply and delivery of drugs over the entire country should be set up. Any failure in meeting the demand generated by public awareness as a result of launching of the campaign will be counter productive, leading to an adverse effect on the campaign as a whole.

The following objectives are to be kept in mind while launching the campaign:

1. To create awareness and interest among the people
2. To develop positive attitudes and practices towards effective action to control and prevent leprosy with available resources and technology.
3. To enlist participation of all sections of the population especially leadership, youth and

women, school and university students (medical nursing social work), teachers and out-of-school youth in the National Leprosy Control Programme.

4. To develop and initiate local voluntary organisations to sustain and promote NLCP by undertaking specific responsibilities

A massive 'swing' has to be generated conducive to people's participation. The communication strategy must be so conceived and implemented as to enliven public enthusiasm and sustain the swing over a long period.

1. HEALTH EDUCATION

Health Education includes the Information, Communication and Educational (ICE) efforts which bring about the desired change in the knowledge, attitudes, beliefs, values and practices related to leprosy, its causation, mode of transmission, methods of treatment and rehabilitation. The basic principle of health education is the belief that every individual, group and community can be educated, if they are provided with learning opportunities and encouraged to participate actively in identifying and assessing the problems, in planning remedial measures and providing facilities to implement these measures. A sound health education programme should be able to generate among the programme personnel and people, self confidence in their mission and programmes.

Health Education involves mass, group or individual media. It includes all institutions and organisations where teaching and learning activities could take place. Therefore, its scope is wide, encompassing all situations and all sections of the population, although the educational efforts are directed to specific target groups according to the nature of the problem and the type of task to be undertaken by the specific groups. Incentives and motivations are identified in the communities according to their social cultural base.

In a traditional community with age long beliefs, customs, taboos and superstitions, it has been found by research that the expected changes could be facilitated by inter personal communication, group discussion and decision, and social support of specific communities. These individual, group and community education efforts, undertaken at the grassroot level by the communication volunteer with adequate supervision and support from higher levels and continued support from mass media efforts will have a greater chance to succeed than isolated disjointed, fragmented information communication and education (ICE) activities. These efforts will

have to be channelled through various media including those of programme personnel who come in contact with the patients, their families and the community.

The District Mobile Training team with a Health Educator, Leprosy Technician and an audio-visual mobile van, will provide, on a continuing basis, the required training, education and technical support in the community.

The total health education efforts which include all ICE activities will be assessed periodically at least once a year, and mid course corrections will be made to meet the new challenges. For this purpose, experts in communications, health education and social science will have to be provided at the state and national levels. These teams will undertake operational research and evaluation studies to assess the efficacy of different mixtures of media and methods and give guidance to refine and develop appropriate methods, community organisation, leadership pattern and traditional media.

2. PUBLIC PARTICIPATION IN LEPROSY ERADICATION

People have to be closely associated with public health programmes as the health measures are meant for their benefit and that of their families and communities. People have their own beliefs and attitudes about the disease and these beliefs are passed on from generation to generation and consequently become second nature to them. Only education can help to drive away such beliefs.

The Government will also have to create an infrastructure for launching the communication campaign on a vertical basis from the national, state, and district to the block level as a component of the programme.

The campaign should be a sustained programme for a fairly long period to bring about the desired change on a permanent basis. It should be continued even after 2000 A.D. Therefore, all available media may be exploited to convey this message and promote a national discussion on leprosy

APPENDIX 2 SYLLABUS FOR TEACHING OF HEALTH EDUCATION FOR (a) MEDICAL OFFICERS AND NON-MEDICAL SUPERVISORS

The subject of health education be covered in 10 lectures. The broad split-up of these is as follows:

Subjects	No. of lectures
1. Teaching and Learning	1
2. Communication	1
3. Health Education	8
Total 10 lectures	10

The matter to be covered in each is given below

1. Teaching & learning:

Lecture-1

Principles of teaching and their application in health education Seven steps in process of learning

2. Communication

Lecture—2

Principles of communication, channels of communication and selection of suitable media.

3. Health Education

Lecture—1

Introduction, definition and development of public health

Lecture—2

Definition, concepts, need of health education

Lecture—3

Principles of health education and objectives of health education

Lecture—4

Methods of health education. One way and Two-way flow

3 Approaches in health education: individual, group and mass.

Lecture—5

Technique of Individual approach Interview or formal discussion

Lecture—6

Technique of group approach, group discussion, group talk or symposium

Lecture 7

Technique of mass approach: Film, Exhibition, or Public talk

Lecture 8

Steps of programme planning:

1. Area characteristics, community characteristics, base line data collection of preliminary information.
2. Local resources, health needs of people, social health programme, community and social welfare organisation
3. Planning and implementation of programme.

(b) PARAMEDICAL WORKER

It is suggested that the subject of Health Education be covered in 20 lectures. The broad split-up of these is as follows:

1. Education: Teaching & learning	2 lectures
2. Communication	2 lectures
3. Sociology	4 lectures
4. Health education	12 lectures

The matter to be covered in each lecture is given below:

1. Education:

Lecture—1:

Principles of teaching and their application to health education activity in leprosy.

Lecture—2:

Principle—five stages in the process of learning and factors which influence it

2. Communication:

Lecture—1:

Principles of communication: Elements in communication and different models.

Lecture—2:

Conditions for effective communication: channels of communication, tools and technique selection of suitable media.

3. Sociology:

Lecture—1:

Sociology: Social structure; relationship between individual and groups: group dynamics

Lecture—2:

Social conformity: Social change—causes of change; changing health behaviour alongwith social change

Lecture—3:

Culture; process of cultural change; concept of

attitude; their formation; change of attitudes and factors inducing such change.

Lecture—4:

Leadership: qualities and attributes; styles of leaders; how to recognise leaders and enlist their co-operation in health education work.

4. Health Education:

Lecture—1:

Introduction, definition and historical development of public health;

Lecture—2:

Introduction-Definition, concepts, importance and need of Health Education in Public Health;

Lecture—3:

Philosophy and principles of Health Education and basic assumptions underlying Health Education and objectives of Health Education;

Lecture—4:

Method of Health Education—Three methods viz: individual, group and mass, selection of the method in relation to the activity, Two methods Didactic or Socratic:

(C) HEALTH EDUCATION TRAINING COURSE

Duration: 2 Months.

Objectives of the training programme:

1. To equip the worker with necessary skills and techniques to carry out intensive leprosy health education in a rural and urban set-up.
2. To enable the worker to provide the necessary guidance for treatment for leprosy patients who come to his knowledge at appropriate treatment centres.
3. To acquaint the worker with the various social needs of the patient/society and to enable him to render appropriate guidance or assistance.
4. To enable the worker to plan, implement and evaluate health education programmes for leprosy.

Curriculum

I. Leprosy (Refresher)

A. Medical aspects.	20
B. Clinic work	20
C. Organisational aspects	5

II. Education

A. Learning	5
B. Teaching	3
C. i) Health Education	18
ii) Health Education	5

III. Social Science	
A. Sociology	16
B. Leadership	5
IV. Communication	
A. Communication	10
B. Public speaking	5
V. Evaluation	
A. Techniques of evaluation	8
B. Statistics	12
Total hours	147
VI. Assignments	
6 Class, 6 Home and 2 Group assignments.	
Trainees prepare interim and final report and submit during the course.	

Field Training

15 days in Urban and Rural area.

- i) Use of flash card and practice of handling it in a small group.
- ii) Use of slides and slide projector.
- iii) Arranging exhibitions and its explanation.
- iv) Contact with mass media, Press, AIR and TV.
- v) Preparation of news and its exploration.
- vi) Contact with formal and informal leaders and to involve them in health educational activities.
- vii) To arrange groups and to address them.
- viii) To contact and arrange refresher course for General Medical Practitioners.
- ix) To present interim report.
- x) To use other media like, street play, puppet show, film show, preparation of slogans and to write in the area. Display of posters judiciously.

Appendix 3

SYLLABUS ON LEPROSY PART IN THE NURSES TRAINING PROGRAMME (FINALISED IN A WORKSHOP UNDER THE JOINT AUSPICES OF GANDHI MEMORIAL LEPROSY FOUNDATION AND WEST BENGAL NURSING COUNCIL)

Total period to be allotted:

Theory 5 hours and practical for 5 hrs.

Unit I

Course content:

Etiology and epidemiology, definition of leprosy causative organism, broad classification lepromatous and non lepromatous infectivity of leprosy, geographical distribution in the State, mode of transmission, incubation period, (factors responsible for the spread of leprosy). —1 day

Unit II:

Signs and symptoms —1 hour
Suggestive signs, diagnostic (cardinal) signs, characteristics of skin lesions in lepromatous and non-lepromatous leprosy, other skin condition stimulating leprosy.

Unit III:

Principles of treatment —1 hour
General considerations, drug of choice, dose schedule, advantages of early treatment, consequences of neglect in early treatment, common complications in leprosy deformities and relation, causes, prevention and correction of deformities, care of anaesthetic hands and feet, care of eyes and nose, signs and symptoms of reaction and its management, management of plantar ulcers.

Unit IV:

Health education and social aspects of leprosy including rehabilitation. Importance of health education in leprosy control programmes, objectives of health education, target groups to be educated, methods and approach, message to convey, nature of problems and its solution, modern concept of rehabilitation. —1 hour

Unit V:

Prevention and control of leprosy —1 hour
a. Prevention—controlling the source of infection, interruption of transmission, protection of susceptibles.
b. Control, model concept, principles of NLCP pattern of work—SET, types of centres.
c. Role of FMPWs in NLCP.

Practical:

1 or 2 field visit, case demonstration —5 hours
testing of sensation with help of ZLO, Medical Officer of Leprosy Control Unit.

Lecture—5:

Technique of individual method-interview, formal discussions

Lecture—6:

Techniques of group method; Group discussion,

panel discussion, flannel show, role-play, symposium, lecture-forum;

Lecture -7:

Techniques of mass method: film show, exhibitions, posters, pamphlets, street-play, puppet show etc.;

Lecture -8:

Steps of programme planning:

- i) Area characteristics, community characteristics, vital statistic, collection of basic data;
- ii) Local resources—coordination and cooperation various agencies catering to health needs of people, on-going social welfare and health programmes, community and social welfare organisations.

Lecture -9:

Programme planning-steps in health education programme, organisation, execution, evaluation types of programmes, incidental, integrated, isolated and crash programmes—follow up.

Lecture -10:

Record maintenance, inferences

Lecture -11

Evaluation-need-importance-utility-types: concurrent and terminal-indicators and tools:

Lecture -12:

Nature of urban leprosy problem-characteristics of urban population—method of leprosy control work suitable for urban area—role of general medical practitioners in leprosy control work.

APPENDIX 4

REFRESHER COURSE FOR PRIVATE PRACTITIONERS

This is based on the Gandhi Memorial Leprosy Foundation's programme for involvement of general medical practitioners conducted in many towns and cities over last fifteen years.

Contents

The course will consist of:—

- i. Four lectures, each of one hour duration
 - ii. Demonstration of patients of different types as may be available locally.
 - iii. Exhibiting coloured transparencies
 - iv. A 20 minute film on "Diagnosis of leprosy".
- The lectures will cover the following subjects though not necessarily in the order given
- (a) Signs and symptoms of leprosy,
 - (b) Complications, c) Pathogenesis of deformities,
 - (d) Actual exacerbations and reaction, (e) Signs of activity and 'inactivity' and 'Arrest' of the disease, (f) Presenting signs,
 - (g) Method of Examination, (h) Differential Diagnosis, (i) treatment, (j) Epidemiology,
 - (k) Prevention.

Duration

The total duration of the course is six working

hours, preferably two hours a day for three days in the afternoon, which is convenient for practitioners to attend. The duration and hours are fixed in consultation with local doctors and IMA. Sometimes, the duration is reduced to five hours, covered in two days.

Follow-up

The agency which conducts the course will keep in close touch with doctors who attend the course to enquire into:

- a) Whether the doctor has confidence in treating a patient of leprosy.
- b) Whether the doctor has confidence in labelling a person as a patient of leprosy.
- c) Whether the doctor needs laboratory services for bacteriological or histopathological investigation, and whether they are locally available
- d) Whether the doctor has detected early cases of leprosy while examining his general clientele for other ailments
- e) Whether the doctor is treating cases noticed in his clinic

APPENDIX 5

INVOLVEMENT OF UNIVERSITIES IN THE STRATEGIES FOR LEPROSY ERADICATION THROUGH NATIONAL SERVICE SCHEME

Though the note is prepared for NSS groups, it will need some modification, be applicable for involvement of youths, women groups, social voluntary agencies, etc.

The Project is, however for students, covered by the National Service Scheme:

Objectives:

- i. To involve the youths in the main National stream of development activities.
- ii. To develop a sense of social commitment.
- iii. To develop health consciousness in the youths specially in respect of leprosy
- iv. To enable the youth to plan and implement the programme in a systematic way.

Keeping in view the above objectives, following programmes under different heads can be taken up in enlisting the co-operation from different groups.

I. Direct help to leprosy patients:

- i. To undertake health education of the

community in respect of leprosy.

- ii. To help and guide early patients of leprosy to proper places of treatment.
- iii. To check whether patients of leprosy are taking treatment regularly.
- iv. To help those leprosy patients who have to suffer social harassment of boycott, and also those in jobs from any injustice or from threat of dismissal on the ground of leprosy.
- v. To raise the funds to provide essential articles to needy patients such as MCR footwear, spectacles, goggles, costly medicines or to help the patient in self employment.
- vi. (a) To visit self settlement colonies to find out their needs and provide them primary needs such as tap water, approach roads, and digging of soak-pits etc.
(b) To help them in constructing a community hall to run a centre for adult education.
(c) To arrange sport competitions in the locality where the leprosy patients stay in group.
- vii. To provide uniforms, books, sport materials for school going children of leprosy patients or child leprosy patients.
- viii. To arrange film shows (Educational films)
- ix. To give all help to local leprosy workers in respect of case detection, treatment, persuasion of absentee/irregular patients and in organising health education programmes.

II. To assist in wiping out the misconception about leprosy:

- i. To launch a campaign to write slogans on the walls with the permission of the house owners.
- ii. To undertake sale of NLO seals and to raise funds for hoardings.
- iii. To organise contests for posters telling the facts of leprosy.
- iv. To arrange film shows, in villages on 'Controlling Leprosy'.
- v. To organise the exhibition on leprosy in public places.
- vi. To distribute free literature about the facts of leprosy
- vii. To participate in anti-leprosy week, from 30th January to 5th February every year.

III. To join in health education campaign for healthy society:

- i. To arrange essay competition for school going children.
- ii. To invite a leprosy worker or a doctor and arrange his talk on leprosy in NSS camps.
- iii. To prepare street plays and stage plays on occasions.
- iv. To include the fact about leprosy in college annual magazines.
- v. To arrange symposia on aspects of leprosy.
- vi. To launch a campaign of pasting posters at public places
- vii. To participate in Anti-Leprosy week (30th January to 5th February) every year.

IV. To select certain study projects of academic interest:

- i. Study of the problems of school going healthy children of leprosy patients.
- ii. Study of children suffering from leprosy and their attendance in leprosy clinics.
- iii. The problems of leprosy patients rehabilitated in colonies.
- iv. The problems of begger leprosy patients and their psychology.
- v. The problems of persons, who are free from leprosy with residual deformities and continuing their life in society.

The central authority of NSS organisation may send the directives to universities to undertake the above projects since leprosy is a major health problem of our country so as to ensure 'HEALTH FOR ALL' in the society by the end of this century.

This scheme can be implemented on two levels- extensive as well as intensive. The co-ordinator of NSS wing at university level must be fully acquainted with the objectives and details of the scheme and its expected results at the community level as well as the students level. Thus the scheme will go through the following phases.

Extensive level:

Preparatory Phase:

Duration 1 year to cover the whole country.

- i. To discuss with the central organisation of NSS at the centre and acquire their consent to introduce the scheme.
- ii. To write letters to all persons incharge at

university level with the enclosed copy of a letter of decision taken by the Central Organisation.

- iii. To plan for a series of workshops at zonal level for different universities to explain the scheme and its utility, and to motivate them.
- iv. To identify the needs for training, planning, execution and to fix up agencies of providing material such as free literature, posters exhibition sets and educational films regarding leprosy.
- v. To work out the details of scheme to be implemented at college level.
- vi. To modify in schemes proposed for extension and intensive level after the workshops are over.

Organisational and implementational Phase:
Duration 2 academic years.

- i. As soon as the workshops are over at zonal level the scheme may be introduced by respective universities.
- ii. Concurrent assessment will be done during the course of implementation and they will be circulated to necessary authorities to find out effectiveness.
- iii. Since the boys remain in NSS unit for 2 years or at the most for 3 years, the duration of the project will be short.
- iv. The incharge of NSS wing at University level is expected to report the work done to Central organisation.

Maintenance and Assessment Phase

- i. The effectiveness of the scheme may be judged by the concurrent assessment and reports sent to the universities.
- ii. After 2 years interval the deserving units (college level) may be invited to know their feelings about the implementation of the scheme and suggestions for necessary modification.
- iii. To alter the scheme if necessary on the basis of suggestions, for further implementation.

Intensive level:

Objectives:

- i. To involve youths in health activities specially in leprosy control work.
- ii. To find out the results through voluntary efforts.

- iii. To create infrastructure for developmental activities at National, State and University level through voluntarism.

After selecting and finalising the list of deserving NSS units at college level the incharge may be called for another workshop to intensify the activities.

Since the financial and administrative burden will be increased in this project the selection will be made very cautiously and judiciously as the funds become available.

The experimental units for intensive work will be selected from each zone. (atleast one from each zone) mainly from endemic area.

Since this project will not work as experimental research project the advice from social scientists may be sought.

Staff Needed:

- i. The incharge of the NSS wing at College level will be main person to handle the scheme.
- ii. Since he is more actively involved in carrying out the scheme, the provision for his honorarium will have to be made in the budget.
- iii. Necessary funds will have to be provided for implementing scheme.

Incharge of NSS wing at College Level: Job-chart

- i. To prepare small projects suitable to local conditions and to get it approved (with financial commitments).
- ii. To fix-up the duration of the projects.
- iii. To assess the projects and report to thier respective universities
- iv. To publish a paper based on the experiments and experiences.

GMLF has developed a Programme for the involvement of NCC Cadets, Bharat Scouts & Guides and two other organised Youth Groups on similar lines.

APPENDIX 6

Consortium of Advertising Agencies:

1. The need for a consortium

Eradication of leprosy in India by 2000 AD is a National programme. In order to achieve this objective it is proposed to launch a nation-wide campaign of mass awareness and mass

participation in the task of Leprosy eradication. The whole project spanning a period of more than a decade is viewed as a 'movement' to mobilise mass support and participation in the programme.

Unlike communication effort in respect of consumer items which calls for generation of 'brand loyalty' resulting in increased sales, communication effort in a Project like Leprosy Eradication calls for a multi-dimensional strategy and approach. It is not a matter of transmitting a single message in different languages in different regions. It is not also a matter of selling a product.

In Leprosy Eradication Programme the objective of communication effort is, primarily education—resulting in the creation of a climate of acceptance of a rational approach to the problem of Leprosy and shedding of prejudices.

In a country like ours, with apart from its vast geographical dimensions, its variety of languages and dialects, its ethnic differences, cultural traditions, its local idioms, its different religious rites and beliefs—communication effort, for leprosy eradication can ill-afford to ignore these differences. It must match its messages to suit regional requirements.

The task is gigantic in its proportions and needs to be undertaken as a co-operative effort and calls for pooling of talent and resources.

Such a pooling of talent and resources can be achieved through the creation of a consortium of Advertising Agencies.

The idea of a number of advertising agencies coming together in launching communication campaigns in support of national and social causes is not new and has been tried successfully before. Such a pooling of resources and talents was successfully tried in India during the Second World War—in support of the National War Front.

2. The role of the 'apex' organisation—GMLF.

The initiative for the creation of such a consortium must come from the GMLF who are the 'apex' body in the Leprosy Eradication Programme.

As a first step 'GMLF' will sound leading advertising agencies in India about their willingness to offer their help in this project.

In 'sounding' these agencies 'GMLF' must assure them that they do not expect the agencies to offer their services free. It must be understood that advertising agencies are not in business for philanthropy—good agencies have social consciousness and are always willing to help social and national causes without putting undue burden on the sponsors.

Once the agencies have been 'sounded', GMLF can prepare a short list of agencies—taking care to see that all the regions of India are properly represented and call a meeting of such agencies to formulate 'modalities' of operations.

The 'Consortium'—needless to say must not have too many agencies—nor should their selection be decided according to their 'billing' figures. More than the size, the willingness of an agency to participate in the programme should be the criterion for selection.

3. How the Consortium will work:

After the consortium is formed, the GMLF should constitute a co-ordination committee comprising of experts in the field of Leprosy, social sciences, health education, communication and other related fields, as well as a representative of advertising agencies in the consortium.

The Co-ordination Committee will be responsible for preparing the brief for the Consortium and serve as a store-house of information about leprosy for the Consortium.

The brief will be common for all the agencies in the consortium but the communication strategy will be tailored to suit, various regional requirements.

The Consortium will submit their proposals to the co-ordination Committee and will discuss their ideas with the Co-ordination Committee—before they are finalised.

The Co-ordination Committee will clearly spell out the objectives of communication effort and their priorities.

APPENDIX 7

A successful experiment in community participation—the Balarampur example

S P. Tare

Leprosy is a disease of antiquity. Due to ignorance about early signs of leprosy, absence of effective medicine over the centuries and the fear in the minds of people due to association of physical disfigurement with those persons recognised as patients of leprosy, this disease was wrapped in mystery and very much abhorred. The leprosy control work which has been carried on in India for quarter of a century now, has yielded some results though not to the desired extent. It is, however, noticed that, by and large, ignorance and social stigma have remained undiminished in vast areas of the country covered by the national programme, as a result of which the social environment continues to inhibit early patients to come forward for diagnosis and advanced patients to retain their jobs and place in society.

In all development activity, we are never tired of talking of people's participation. In all health activity also, the need for people's participation is always stressed. But there is a great reservation in some of the methods implemented for motivating this participation. Often the planners identify exactly how people should participate in the programme. They give so great an importance to people's participation that they are unwilling to leave it to the people themselves. Naturally, they prepare a fool-proof plan for participation of people and when their plan is ready, they go to the people and instruct them how they must participate in the programme. They are, eventually, baffled when they notice, that people are not participating in the manner in which they were instructed to. Behind all this exercise lies the belief that people do not know what is best for them and are not capable of taking decisions in matters which concern them.

The error in this format lies in the disbelief that people, left to themselves are wise enough and if

guided discreetly and suitably, are capable of understanding what is best for them. We forget that the concept of people's participation entails enhancing of the capacities of rural communities, to take responsibility on their own for their health.

The Gandhi Memorial Leprosy Foundation started an experimental leprosy control unit in Balarampur in Purulia District of West Bengal to try out alternatives of case detection, health education and treatment in order to achieve the objectives of leprosy control in a quicker way. One area comprising 90 villages and covering a population of about 60,000 was set apart for alternatives of educational interventions one of which is involving people in leprosy work.

In the Balarampur Control Unit's Zone C which was set apart for trying out different methods of health education, a unique experiment was conducted to enlist people's participation. It was decided to leave the activity of health education to the people. It was also decided that, the leprosy worker will only conduct clinics and give treatment, whereas health education will only be done by contact persons and new cases will come voluntarily forward.

For this, the worker identified in selected houses the person whom the family consulted for solving domestic problems. The term, 'leader' or 'local leader' was avoided because of the political connotations.

The names which came up were quite often, of such persons who had no special status not held any political or other post in the village, but they were persons on whom most of the villagers looked up to for guidance.

As a second step, these contact persons were informed about the leprosy problem in their district and of the work being done in the area. The discussions were very informal, and friendly. The group, came forward with suggestions, in very simple language, as to what they can do. These suggestions were again discussed, and were accepted.

The Para Medical Workers operating in these areas were withdrawn from active case-finding and health education. Only general information, guidance and aids, if requested were offered. An evaluation of the activities of the contact person was done, also in informal way, a fortnight later, by the PMW's.

The findings were that:

- None of the contact persons asked for any help from the workers while actually dealing with

the problems. But they discussed some problems to get their doubts cleared and gathered maximum information and rational arguments to deal with the doubt cleared and gathered maximum information and rational arguments to deal with the doubts raised by the people.

- None of the contact persons asked the workers to address any meetings, nor did they seek any of the health educational aids.
- From the experiment area, 275, cases reported voluntary while in the area which adopted conventional methods, 228 cases were detected.
- Voluntary reporting with the help of community participation was significantly higher (P less than .05) than through conventional methods. These results indicate that the participation of contact persons has succeeded in bringing more early cases, voluntarily for diagnosis and treatment.

Confronted with these series of unbelievably encouraging instances, an effort was made to learn from the involved contact persons as to how they have done health education in their community which has brought about such a revealing change. These contact persons however, found it difficult to articulate; they merely said that they have hardly done anything except casually speaking with people and informing them what they not know and believe about leprosy. They have not held any formal or informal meetings. We can only infer that they could do this because:

1. They are part of the same community, unlike the leprosy worker who is an 'out-sider' to community.
2. They speak the same language as all other people in that community; unlike the leprosy worker who speaks a different sophisticated language.
3. They are doing all this on their own initiative and commitment; unlike the leprosy worker who, quite often, may lack such commitment.
4. They are looked upon as 'un-interested' persons by the community and hence their word carries more weight with people unlike that of a leprosy worker who is known to be paid for what he is doing and what he talks.

These findings no doubt bring out the fact that voluntary participation is better achieved by leaving the initiative to the participants—

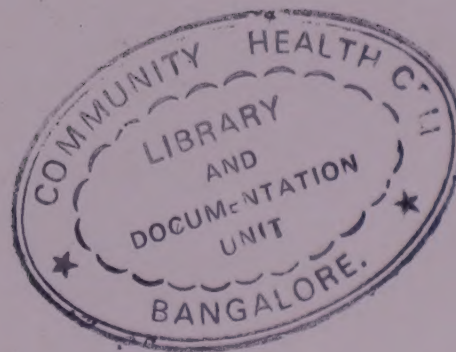
without imposing advice and guidance from above—and taking them in confidence. What is perhaps more important is that such voluntary participation leads finally to the total involvement of the people in any programme as will be seen from several incidents which dramatically demonstrate the element of total involvement of the people.

1. One event occurred in Ransi village of Tumrasol Anchal where Surendra Mahato, a patient of leprosy, was not allowed by Shibnath, a rich farmer, to draw water from the village pond. Shibnath is also reported to have used abusive language while addressing Mahato, who narrated this incident to Kalipade Bannerjee, our contact person in Ransi village. Bannerjee, first made efforts to persuade Shibnath, but failing that, took the initiative to convene a Gram Sabha (meeting of adults in the village) to discuss this. After Mahato and Shibnath spoke, some villagers addressed the gathering to stress that there is no risk if a patient draws water from the pond. The meeting not only unanimously endorsed this view but also imposed a fine of Rs. 10/- on Shibnath for using abusive language while talking to a patient of leprosy. Our worker heard of this episode a week later when he visited the village.
2. The other incident occurred in the village Girihari where father of Aditya Kaibarta, a patient of leprosy, expired. It was necessary, according to Hindu tradition, that Aditya's head is fully shaved before he performs the funeral rites, Girihari being a small village. Abhoy Pramanik, a barber of nearby bigger village, was summoned, but on recognising Aditya as a patient of leprosy, Abhoy refused to shave him. Entire population of Girihari village was present. There were efforts to convince Pramanik by arguments but he remained adamant. Finally, Kalipada Mahata, the contact person of Girihari village, offered that he will get himself shaved after Aditya is shaved, to convince Pramanik that his fears that others will not accept his services are baseless. Pramanik accepted this and, in the presence of all villagers, he first shaved Aditya and then Kalipada and the funeral rites were duly performed. One may have doubts whether what Kalipada did was the right decision, but we must realise what Kalipada did on the spur of the moment was a solution devised to meet the stalemate arising out of the prejudices shown by the barber.

These are only two representative events, but similar instances, though not equally dramatic, have occurred in the villages of Patpur,

Bonkathi, Purishase, Latpada, Housladih, Bhaluidh and Sindri where the community has rallied to support a leprosy patient from instances of social harassment.

Though it may be too early to assess the impact of this experiment in Leprosy Control, there is reason to feel the trend may prove irreversible and may finally result in developing a more sympathetic and rational approach to leprosy and create a benign atmosphere for the patient of leprosy. It is mainly so, because the inspiration to understand the true nature of leprosy has sprung from within the people. A villager no matter how illiterate he is, or what his social status is in the village has proved that once he is convinced of the utility of a programme he is in a better position to deliver the goods more effectively and in a shorter span of time. Here he knows that he is the master of his own destiny and can achieve his goal more speedily than if he were constantly guided and advised by outside experts.



Edited by : S. P. Tare
Published by The Director, Gandhi Memorial Leprosy Foundation, Hindinagar, Wardha, Maharashtra. Designed and
Produced by Spectrum Communications, New Delhi. Printed at Veerendra Printers, New Delhi. Copy/Editorial
Consultants: R.Ajith Kumar/P.D.Abhyankar, New Delhi.

**GANDHI MEMORIAL
LEPROSY FOUNDATION**

**HINDI NAGAR, WARDHA-442103
MAHARASHTRA**